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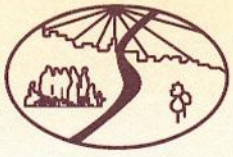
Common Functional Assessment and Disability-Related Agencies and Departments in Saskatoon

by Wendy MacDermott



Building Healthy Sustainable Communities

Community-University Institute for Social Research

CUISR is a partnership between a set of community-based organizations (including Saskatoon District Health, the City of Saskatoon, Quint Development Corporation, the Saskatoon Regional Intersectoral Committee on Human Services) and a large number of faculty and graduate students from the University of Saskatchewan. CUISR's mission is "to serve as a focal point for community-based research and to integrate the various social research needs and experiential knowledge of the community-based organizations with the technical expertise available at the University. It promotes, undertakes, and critically evaluatea applied social research for community-based organizations, and serves as a data clearinghouse for applied and community-based social research. The overall goal of CUISR is to build the capacity of researchers, community-based organizations and citizenry to enhance community quality of life."

This mission is reflected in the following objectives: (1) to build capacity within CBOs to conduct their own applied social research and write grant proposals; (2) to serve as a conduit for the transfer of experientially-based knowledge from the community to the University classroom, and transfer technical expertise from the University to the community and CBOs; (3) to provide CBOs with assistance in the areas of survey sample design, estimation and data analysis, or, where necessary, to undertake survey research that is timely, accurate and reliable; (4) to serve as a central clearinghouse, or data warehouse, for community-based and applied social research findings; and (5) to allow members of the University and CBOs to access a broad range of data over a long time period.

As a starting point, CUISR has established three focused research modules in the areas of Community Health Determinants and Health Policy, Community Economic Development, and Quality of Life Indicators. The three-pronged research thrust underlying the proposed Institute is, in operational terms, highly integrated. The central questions in the three modules—community quality of life, health, and economy—are so interdependent that many of the projects and partners already span and work in more than one module. All of this research is focused on creating and maintaining healthy, sustainable communities.

Research is the driving force that cements the partnership between universities, CBOs, and government in acquiring, transferring, and applying knowledge in the form of policy and programs. Researchers within each of the modules examine these dimensions from their particular perspective, and the results are integrated at the level of the Institute, thus providing a rich, multi-faceted analysis of the common social and economic issues. The integrated results are then communicated to the Community and the University in a number of ways to ensure that research makes a difference in the development of services, implementation of policy, and lives of the people of Saskatoon and Saskatchewan.

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Abstract

This document describes development of the Common Functional Assessment (CFA) tool. The CFA tool was developed to assess children with disabilities in terms of their needs to obtain more information than available from a medical or psychological diagnosis or Intelligence Quotient (IQ) tests. This tool was developed in consultation with many disability-related agency representatives and parents. Descriptions of various stakeholder disability-related agencies involved in construction of the CFA tool are included.

Introduction

On 20 April 1999, Saskatoon Communities for Children (SCC) formally adopted a major package of recommendations developed by its Disabilities Working Group entitled, *Recommended Changes to the System of 24 Hour Care to Support Children with Disabilities and their Families in the Saskatoon Region and in the Province of Saskatchewan.* (Unless otherwise noted, all direct quotes in this report come from this document.) A key recommendation of this package is "that the principle of basing eligibility criteria more on function and less on a single diagnostic criterion be applied to the provision of all services aimed at providing 24 hour care/support for children with disabilities and their families, including respite services, noon hour supervision support, before and after school care, and specialized day care." Further, SCC recommends that "we work towards having one common functional assessment that all organizations agree will be used as a decision-making framework to assess eligibility for access to 24 hour care services."

Saskatoon Communities for Children, in collaboration with the Community-University Institute for Social Research (CUISR), commissioned research to develop recommendations for a common functional assessment tool for the Saskatoon region. Over the course of three months, existing assessment tools were reviewed and a broad range of community stakeholders consulted.

Saskatoon Communities for Children is a non-profit organization that brings together various stakeholders to identify and address issues that affect Saskatoon children (e.g. poverty, disabilities, school non-attendance). SCC does not provide direct services, but rather brings together various integral partners and provides guidance. Saskatoon Communities for Children's pivotal strength is that all stakeholders are represented (par-

ents, community members, non government agencies, and government officials, both civic and provincial). With all voices represented, efforts at change are more likely to be appropriate and administered adequately.

The Disabilities Working Group is a partnership of children with disabilities and their parents, non-government agencies that deliver services to children with disabilities and their families, and government agencies that provide financial support or services to children with disabilities and their families. "It is the ultimate hope of the Disabilities Working Group that we can move towards the seamless delivery of services to children with a disability and their families, with access to services being based on a functional assessment of each child" (Recommended Changes to the System of 24 Hour Care to Support Children with Disabilities and their Families in the Saskatoon Region and in the Province of Saskatchewan**,** 2000).

This common functional measure was developed to assess the broad needs of children with disabilities and their families. "The basic purpose of a functional assessment would be to look at the broader needs of a child and his/her family when making a judgement about access to services, rather than building the gateway to services only around a very specific criteria or a specific diagnosis. A functional assessment still relies on diagnosis but that diagnosis is more broadly based. It is intended that the assessment be ongoing, so that the changing needs and abilities of the child are taken into account. A common functional assessment would take into account factors such as deficits in age appropriate behaviour, physical mobility of the child, level of independence of the child, psychiatric needs of the child, stress on the family, financial stress facing the family, and equipment needs of the child" (Recommended Changes to the System of 24 Hour Care to Support Children with Disabilities and their Families in the Saskatoon Region and in the Province of Saskatchewan, 2000).

Many who are involved with disabled children report that providing services based solely on medical or psychiatric diagnoses or Intelligence Quotient does not reflect children's unique needs. Indeed, many children whose needs are high appear to be "falling through the cracks" because they do not meet current mandates that require conventional diagnosis or a low IQ score. It is hoped that this measure will provide a more comprehensive assessment of children's needs and situations. Furthermore, this assessment should help government and non-government agencies that provide service or support to the families of children with disabilities determine the needs and extent of services of a child. In order to be most effective, this measure should take into account both the family's and child's needs. It is important to avoid assessing the child's needs in isolation.

Representatives from the following sectors were consulted as part of the work to develop this recommendation: parents of children with disabilities; Saskatoon Catholic School Division; Saskatoon East School Division; Child and Youth Services; Commu-

nity Living Division (Saskatchewan Social Services); Saskatoon Association for Community Living; Child Day Care Branch (Saskatchewan Social Services); Alvin Buckwold Child Development Program (Saskatoon District Health); and the Coordinated Assessment Unit (Saskatoon District Health). Assessment tools used by these organizations were collected and analyzed. The present tool is intended to reflect components of those tools.

Why a Common Functional Assessment Tool?

Present Eligibility Criteria Limit Access to Children in Need and Lack of Services

Professionals who provide services to children with disabilities reported that many were unable to access services because they did not meet criteria or mandates. Some also reported that many of these children have very high needs: "In the past few years we have lost a child to the streets and many Fetal Alcohol Effect children as wards of the courts. Some ask what happens if we open the door to all kids. The answer is we are paying for it in other ways anyhow (e.g. justice, social services)."

Some professionals indicated that services to meet some children's needs (e.g. Fetal Alcohol Syndrome of Effect (FAS), Attention Deficit problems, or Asperger's Syndrome) simply do not exist: "I would see a problem not with accessibility but we do not have different (specialized) services. The services are not refined enough. We are a generalized service. I would like to see … staff have training in behaviour management and for the staff to be willing and able to work with these difficulties. I think these kids are higher needs than most. I would like to see group homes for kids to get respite. There don't seem to be any services for these kids. We're looking at Sherbrook which is for acquired brain injury but it is for young adults. We need more people trained to deal with emotional and behavioural difficulties."

Parents echoed concerns expressed above: "Base criteria on abilities not IQ. Then she could have had supportive living or even respite for us. Respite would have helped us. I know there is some available (through mental health). They [children with FAS] don't qualify anywhere. Now it seems to be looking up a little bit, it has taken so long. We're trying to get him into COSMO but it has taken two and a half years. It has taken so long because his IQ is not low enough. It was not in Community Living Division mandate. Our son was hospitalized and then Mental Health got involved."

Facilitate Integrated Service Delivery and Decrease Redundancy (Intake, Assessment)

Professionals also felt that increasing service integration and cooperation would benefit disabled children's well being: "Because the [Common Functional Assessment] tool reflects thinking in organizations, it will remove walls and make it easier to navigate through the system. We need more integration of services. If we could pull services together around the tool it would be good. We need to develop co-ordinated treatment plans. We need to use a model of integrated services centred in the schools. Have professionals work in the schools and out of their clinics. We need to have interdisciplinary teams. The most difficult challenge is asking families to access services. They fear the setting and accessibility is a problem."

Parents also expressed frustration with a seemingly fragmented system:

- "I don't know why Mental Health and Community Living Division don't work together rather than separate. It is not helping the people they are out to help."
- "The problem where these kids are falling through the cracks is that they are mobile and they look healthy."
- "If [FAS] had been diagnosed earlier we could have prevented secondary disabilities like alcohol and drug problems and supported living. I think professional people were not aware of FAS and its disabilities, learning disability. Her disability is very hidden when you talk to her. You do not see it unless you live with her."

Professionals and parents alike recommended three ways to better help children with disabilities:

(1) Provide assessment and subsequent services based on needs.

(2) Needs should include and acknowledge the importance of behavioural and emotional difficulties, and, in particular aggressiveness and safety issues.

(3) Include the family in assessment and collect information relevant to familial context.

Disability-Related Services in Saskatoon, Who They Serve, and What They Provide

This list of disability-related agencies is not comprehensive, but is based on data provided from interviews with various stakeholders during the development of the Common Functional Assessment tool.

Saskatoon Catholic School Division

The Catholic School Division provides services to all children attending their schools. Learning assistance teachers, speech and language pathologists, itinerant teachers for

students with sensory impairments, teacher assistants, and technical aides provide programming support for students with diverse needs.

Programs for students with diverse needs are developed using a collaborative team approach, including parents, classroom teachers, learning assistance teacher, teacher assistants, and may include community agency representatives.

Saskatoon East School Division

The East School Division provides psychological, educational, and academic assessment. They also seek to meet student needs by providing adapted, modified, and alternate programming. A child is able to manage regular curriculum with adapted programming if different teaching strategies are utilized. Modified programming is fundamentally different from regular programming, with only 50% of regular content covered. Alternate programming is functional life skills programming. Congregation only occurs with youth aged 15 to 18 years. The East School Division believes in inclusionary, community education, and strength- and needs-based evaluation. Occupational therapists and physiotherapists from the Kinsmen Children Center are contracted to work in the schools. Psychiatrists perform medical-based diagnoses, but their emphasis is on needs.

Funding remains dependent on medical or psychiatric diagnosis and is subject to funding criteria.

Child and Youth Mental Health

Saskatchewan Mental Health provides services to children in three age categories—0-5, 6-11, and 12-18 years. The intake process is centralized and children / youth are referred to appropriate services through that process. The initial referral, however, can come from a parent, doctor, teacher, or social worker.

Child and Youth Mental Health provides individual, family, and group counselling, as well as assessment of young offenders referred by the court. The youth resource centre also has a day program for youth who require stabilization before returning to the school system. They also provide a variety of group youth services. The caseload at Saskatchewan Mental Health is composed predominantly of children experiencing depression, behavioural problems, and mental disorders.

Community Living Division (Social Services)

According to *About*, the Department of Social Services newsletter, the main objective of the Community Living Division is to ensure that physical, emotional, and social needs are met, and that people with intellectual disabilities live and function as independently as possible within their own communities. Community Living Division services are available to Saskatchewan residents who meet the criteria of mental retardation, as set out by the American Association on Mental Retardation in 1983. These include significantly subaverage intellectual function (below 70 IQ) and impairments in adap-

tive behaviour (limitations in developmental expectation) as manifested during the developmental period (before 18th birthday).

The Community Living Division offers social work case management (assessment, counselling, and planning); program development consultant services (determine needed services, provide leadership in program development, program monitoring, implementation, and evaluation of care provider training); and liaison with Community-based organizations (provide funding to residential services—group homes, supportive independent living programs, supported apartment living programs, group living homes, Valley View Center, and Family Support Services—respite, early childhood intervention, Developmental and Functional Life Skills Services, and Employment/Transitional Training Services.

Saskatoon Association for Community Living (SACL)

SACL's basic mission is "to advocate for all persons with intellectual disabilities and their families in the areas of education, housing, employment/day programs, respite and leisure." SACL also provides such direct services as: respite coordination for children; winter recreation program; summer camps (teen activities, kids adventure, enriched care and Parkridge Peds Program); and winter recreation programs for children and adults.

To access these services an application form is completed. However, there are no eligibility criteria. Staff ask that individuals "try out" the service to see if it meets their interest. However, in order to access funding, individuals must meet Community Living Division of Social Service's mandate (e.g. under-70 IQ).

Child Day Care Branch (Social Services)

The Child Day Care Division does not provide direct services to children, but rather licenses and monitors child care facilities and provides support to caregivers. In cooperation with Saskatoon District Health, two early childhood psychologists, a speech pathologist, and two language pathologists work exclusively with registered day cares.

As one staff member said, "One of the supports we provide is the Child Development Grant Program which provides funding for child care facilities to enable them to provide care to children with special needs." Services are currently determined by a functional assessment based on the child's level of need. A functional assessment is conducted and an application submitted. There are also Enhanced Accessibility Grants to supplement Child Development Grants. Pilot projects are underway to investigate the effectiveness of providing block funding to day cares that accommodate disabled children. The intent is to decrease the amount of time spent applying for grants, enabling staff to spend more time with children. If up to 15% of the children in the day care are "disabled," the facility can receive the block funding. No particular referral mechanisms are in place, allowing any child to attend this particular day care. One pilot day

care reported much satisfaction with this new process. However, the pilot program had only been underway for three months.

Alvin Buckwold Child Development Program (ANCDP) (Saskatoon District Health)

The Alvin Buckwold Child Development Program offers diagnostic and treatment to children, youth, and their families living in Central or Northern Saskatchewan. Programming is predominantly for children with developmental delays and disabilities, and also for children at risk for developmental problems (e.g. acquired brain injury, amputations, cerebral palsy, fetal alcohol syndrome, or muscular dystrophy). Children and youth can only access these services by physician's referral.

ABCDP offers: speech and language development; sensory and motor development; educational programming; feeding; behaviour management; bowel and bladder functioning; specialized equipment; locating appropriate resources; and social-emotional adjustment to disability.

ABCDP utilizes a team approach. Staff includes dietitians, nurses, pediatric occupational therapists, pediatric physiotherapists, physicians, psychologists, social workers, speech and language pathologists, and therapy attendants. The program also collaborates with services in the community, including geneticists, neurosurgeons, orthopedic surgeons, pediatric neurologists, orthotists, and urologists.

Coordinated Assessment Unit (CAU) (Saskatoon District Health)

The Coordinated Assessment Unit is a single entry case management service designed to provide information about, and access to, a variety of resources within Saskatoon District Health. It is also designed to provide liaison between a wide variety of resources and ongoing monitoring and support of clients through a case management model. Client Care Coordinators are based in urban, rural, acute, and long term care sectors.

CAU provides information and arranges access to the following services and programs for elderly, ill, or disabled individuals: community social work; community occupational therapy; community physical therapy; community day programs; special care homes; home care services; information on personal care homes; information on enriched housing opportunities; and information on other available community resources.

Development of the Common Functional Assessment Tool

The following section outlines the process taken to develop the Common Functional Assessment tool.

An initial meeting was held with the Common Functional Assessment sub-committee of the Disabilities Working Group of Saskatoon Communities for Children. This

committee outlined needs for such a measure and goals that the tool was intended to accomplish. Representatives from the Saskatoon Tribal Council, Child Day Care Division, Catholic School System, Community Living Division, Saskatoon Association for Community Living, and the SDH Coordinated Assessment Unit attended this meeting. From this meeting, it was decided that stakeholders be interviewed to determine what should be included in the tool and whether any appropriate assessment tools existed, a literature review be conducted to uncover tools that may be appropriate, and indicators of "normal" development to be used in the Assessment Tool be identified. The Child Day Care representative also provided recently modified assessment measures for examination.

From this meeting it was determined that the CFA tool was intended as an initial screening tool to illustrate each child's unique needs. This tool should be used to complement, not replace, existing tools within an agency. In order to cover behaviour, many aspects, the CFA tool could not inspect minute details. Needs not currently being assessed, yet significantly impacting children with disabilities and their families, include: safety concerns, such as knowing one's telephone number or understanding that a stove is hot; aggressive behaviour (injurious to self or others); sexual behaviours; and family support needs. The ultimate outcome of the CFA tool is to provide evidence that many extensive needs children are ineligible for services, and be a catalyst to encourage agencies and departments to modify their mandates and policies to better meet the needs of children with disabilities and their families.

Literature Review

The literature review revealed that there were no tools able to assess adaptation of children with any disability. Many assessment tools were disability dependent. A number of clinical (developmental) psychologists suggested that the Vineland technique (an assessment tool that investigates functioning) might approximate CFA's vision. However, in order to utilize the Vineland, the person who administers the test must be trained in psychometrics and psychological assessment, which minimizes utility in many forums. Furthermore, the Vineland is highly standardized and leaves little room for variance. According to one professional who utilizes the Vineland, "It is a useful tool. It shows what kids are like in everyday life. If it is used you are going to have to choose a cut off. It is not great at targeting Aspergers and aggression behaviour problems. It captures adaptive skills not behaviours." Although the Vineland was not recommended to the Disabilities Working Group, it was considered when developing the CFA tool to ensure that many aspects of behaviour were captured.

Interviews

Interviews were conducted with various stakeholders to better understand the need for such a tool, how it should be utilized, and what it should entail. Interviews were con-

ducted with various professionals (SACL, CLD, ABCDP, East School Division, Child Day Care Division, a Day Care worker, Catholic School Division, Coordinated Assessment Unit (SDH), and Child and Youth Services). These professionals were asked what services they provide to children with disabilities; how children gain access to the services and whether this process is adequate; what additional information would help them better meet children's needs; how to make services more accessible to children who are "falling through the cracks"; whether they would use a CFA tool (and, if not, what they would need in order to use the tool); and what information the tool should provide them (see **Appendix A** for interview questions).

After each interview, an inquiry was made about assessment (intake) tools. Information was requested about these tools to include components from each, so as to increase the measure's utility. Therefore, the measure is based on assessment tools currently in use.

Interviews were also conducted with parents to understand their children's needs. Only three parents were available to interview due to their own busy schedules. Parents were asked what services their children had used, how they had accessed the services, whether this process was adequate, suggestions for improving accessibility of services, what information would be helpful, and what the CFA tool should contain.

Results

The current CFA tool is based on existing tools. New sections were generated based on interview suggestions and recommendations. The first draft of the CFA tool was sent to a parent and the Disabilities Working Group chair for evaluation. Revisions were suggested in terms of format and language. For example, the word "probe" was replaced with "reminder." Some sections were condensed, while others were elaborated upon and clarified.

A draft of the CFA tool was then presented to the Disabilities Working Group of Saskatoon Communities for Children and feedback requested. Initial reactions suggested developing a users manual to provide additional information to individuals who would administer the tool. Other minor modifications included inclusion of questions related to sleep and language/speech difficulties, space for additional comments, and clarification of scoring.

Future Considerations

The following are some suggestions for the next step. Some arise from conversations with, and suggestions from, stakeholders. Others have developed from a struggle to understand the pragmatics of how best to utilize the CFA tool.

Establish Consensus on Utilization of CFA Tool

In order to ensure that this tool is utilized to its optimum potential, all stakeholder agencies must know how to, and, more importantly, agree to use the tool. One suggestion that all parties agreed upon was that the tool should be used as a preliminary assessment to help children gain access to services, and that agencies would continue to use a more "tailored" assessment based on service type. The following are suggestions for CFA tool implementation. Some of these methods would entail substantial remodeling of existing social infrastructure.

First, the tool could be utilized by the organization with which a family has initial contact. The CFA tool could be administered to determine what services might be needed and what agency could provide them. The CFA tool could be computerized and a secure website created so that each stakeholder agency has access family information. This could decrease redundancy and stress experienced by families having to repeatedly describe the same problems. This concern was expressed at 28 March 2000 Disabilities Working Group meeting: "It was also suggested that this CFA tool would follow a child with disabilities and their family from service to service, and would provide a kind of 'heads-up' to each organization about the child's special needs."

Second, a centralized intake could be developed to conduct a preliminary assessment using the CFA tool, and then refer the family to the appropriate agencies. There could be one central intake, or a number of coordinated intakes, at the community level. This suggestion is consistent with the following recommendation submitted by the Disability Working Group: "That all organizations involved in the care of children with a disability come together to plan how we can achieve central coordination around the availability of specialized 24 hour a day 'care services' to each child with a disability in the Saskatoon Region."

These suggestions would require mandate changes at all levels of agency and government to accommodate children not presently eligible to access services.

In summary, the CFA tool should be utilized in such a way to ensure that children and families needing support have their needs met, and to reduce redundancy in assessment as families access multiple services.

Scoring

The CFA tool should be used to flag particular difficulties in children with disabilities. The score a child receives on this measure should not determine whether he/she receives services. Scoring of this measure is not extensive because a particular number may misrepresent a family's situation. For example, a child may score "well" in all areas but safety. Overall, the child would have a "good" score, but the child and his/her family may, nevertheless, have extensive needs. At present, there is some division within

the Working Group regarding this issue. One stakeholder suggested that if scoring were necessary, a range should be adopted rather than a "magic number" that determines who needs services.

Develop Training Workshops to Administer the Tool

Although the CFA tool was designed to be user-friendly and free of jargon and technical information, those using it should be familiar with the reasons for its development and intended purpose. Furthermore, sections and items should be explained to potential users to better understand how to use the tool. Working Group members have also suggested developing a user's manual for the CFA tool.

Pilot Test the Tool for Reliability, Validity, and User Friendliness

The CFA tool should undergo further pilot testing and revision to determine its reliability (does it provide the same results repeatedly when assessing the same individual?), validity (is it measuring what it is intended to measure?), and user-friendly capacity (can frontline workers and managers utilize this tool with success?).

A local daycare and a parent utilized the CFA tool to determine whether the tool was appropriate and revealed relevant information. Both mother and worker provided suggestions that resulted in adaptations of the CFA tool. These suggestions pertained to more detailed instructions and addition of another question regarding language needs. More piloting is regarded as necessary.

The Working Group has recommended parameters for the pilot testing. The testing should be inter-sectoral (i.e. include all stakeholder agencies); include rural and urban services and families; be used as a common tool by all agencies as a referral mechanism and as a structured interview; and be evaluated by those familiar with the measure and process.

Evaluation of the CFA Tool

Evaluation should be conducted to ensure that the CFA tool meets its prescribed goals (i.e. to facilitate accessibility of services to children not currently receiving services and to reduce redundancy and parents repeatedly answering the same questions). This evaluation should also demonstrate that the assessment tool is being administered correctly and to verify the tool's psychometric properties. Furthermore, this investigation should include families and services in both rural and urban areas.

Appendix A. Interview Questions for Professionals.

1) What services do you provide children with disabilities?

2) How do children gain access to these services? How do you determine a child can utilize services?

3) To what extent do you feel this is an adequate system? If you feel your current system is inadequate, could you recommend a better approach?

4) What additional information would enable you to best meet the needs of children? What information would help you to determine when a child is in need of your services?

5) It has been found that children with emotional/behavioural problems (e.g. ADD, ADHD, FAE, FAS, Aspergers, and aggression) are unable to access many services. What suggestions do you have to make your services more accessible to all children in need?

6a) If a common functional assessment tool were available to assess children's needs, not solely dependent on IQ or psychological and medical diagnoses, would/could your agency use this tool in addition to your current system of determining service eligibility?

6b) Would this tool enable your agency to provide services to children who are "falling through the cracks"?

6c) If no, what would your agency need in order to utilize such an assessment tool?

6d) What specific information should this tool provide to you? (e.g. eat independently by x age? …)

Appendix B. Interview Questions for Parents.

1) What services related to her/his disability do you or your child access?

2) How did you come to access these services? Could you please describe the process involved in accessing these services?

3) To what extent do you feel this process met your needs? If you were dissatisfied, could you recommend a better approach?

4) What information would better enable your child to receive the support she/he needs?

5) It has been found that children with emotional/behavioural problems (e.g. ADD, ADHD, FAE, FAS, Aspergers, and aggression) are unable to access many services. What suggestions do you have to make services more accessible to all children in need?

6a) How might a common functional assessment tool, to assess children's needs, not solely dependent on IQ or psychological and medical diagnoses, improve accessibility of services for children who are currently "falling through the cracks'?

6b) What domains should be included that are not presently included in assessments to determine service accessibility?

6c) What other recommendations, suggestions do you have for the proposed assessment tool?

Appendix C. Draft of the CFA Tool Recommendation.

Saskatoon Communities for Children
and the Community University Institute for Social Research
Recommendation for a
Common Functional Assessment Tool for
Children with Disabilities and their Families
March 28, 2001 [DRAFT]

Introduction

On April 20, 1999, Saskatoon Communities for Children formally adopted a major package of recommendations developed by its Disabilities Working Group entitled, "Recommended Changes to the System of 24 Hour Care to Support Children with Disabilities and their Families in the Saskatoon Region and in the Province of Saskatchewan." A key recommendation of this package is that "the principle of basing eligibility criteria more on function and less on a single diagnostic criterion be applied to the provision of all services aimed at providing 24 hour care/support for children with disabilities and their families, including respite services, noon hour supervision support, before and after school care, and specialized day care." Further, Saskatoon Communities for Children recommends that "we work towards having one common functional assessment that all organizations agree will be used as a decision-making framework to assess eligibility for access to 24 hour care services."

Saskatoon Communities for Children, in collaboration with CUISR (Community-University Institute for Social Research), hired a researcher to develop a recommendation for a common functional assessment tool for the Saskatoon region. Over the past three months, Wendy MacDermott has reviewed existing assessment tools and consulted with a broad range of stakeholders in our community (see below). This document is the result of her research.

This common functional measure was developed to assess the broad needs of children with disabilities and their families. Many who are involved with disabled children report that services based solely on medical or psychiatric diagnosis or IQ (Intelligence Quotient) do not reflect the unique needs of children. Indeed, many children whose needs are high appear to be "falling through the cracks" because they do not meet current mandates that require diagnosis or low IQ. It is hoped that this measure will provide a more comprehensive assessment of children's needs and situations, and that it will help government and non-government organizations that deliver services and/or provide financial support to children with disabilities and their families to better determine what services a child needs and how much of the service is required. In order to be most effective, this measure should take into account the needs of the family as

well as those of the child. It is important to avoid assessing the needs of the child in isolation.

Representatives from the following sectors were consulted as part of the work to develop this recommendation: parents of children with disabilities; Saskatoon Catholic School Division; Saskatoon East School Division; Adolescent Mental Health (Saskatoon District Health); Community Living Division (SK Social Services); Saskatoon Association for Community Living; Child Day Care Branch (SK Social Services); Alvin Buckwold Child Development Program (Saskatoon District Health); and the Coordinated Assessment Unit (Saskatoon District Health). Assessment tools used by many of these organizations were collected and analyzed; the present tool is intended to reflect components of those tools.

How to Use the Common Functional Assessment Tool

This measure has been developed to be as efficient as possible. Therefore, at the beginning of each section there is an introductory question to determine whether the section applies to the needs of the child. If the section (e.g., personal care) is not an issue for the child, skip to the next section as indicated. By the same token, if the family does not require support, skip the open ended section as well. The last three sections do not have 'skip' options and should be completed.

The first question in each section relates to age appropriateness. Responses to these questions will enable developmental issues to emerge. For instance, it is age appropriate for an infant to require feeding by a caregiver; it is not, however, age appropriate for an adolescent to need to be fed. Check the appropriate response to each question.

For each question there is also a "relative importance of needs" question. This indicates how much the particular need affects the family and/or child. A number from 1 to 5 should be placed in this space. 1 represents no burden, 2 represents occasional difficulties, 3 represents continual, but manageable difficulties, 4 represents continual and sometimes unmanageable (need occasional support), and 5 represents over burdened (need ongoing support).

The score of the relative importance should be multiplied by the number of the response chosen. This product should be written in the space following the word 'Total' in the comments portion of the question.

Most questions are include a comments option where those completing the assessment can include additional information.

At the end of each section, space has been provided to allow the person conducting the assessment to begin to develop an action plan for the child and family. The needs of the family and appropriate services are identified. This section may be especially useful if representatives from several organizations are involved in the assessment. This section provides an opportunity to identify "who can do what".

Sections D and E include "check list" questions where more than one response may be appropriate. Check off as many responses as apply.

Scoring

The relative impacts options can range from one to five and should be included for all relevant questions. The responses to questions are placed in order of adaptation (low numbers indicate regular developmental adaptation). These two numbers should be multiplied and the total placed in the spaced marked 'total'. The total scores for each section should be added and placed on the final page in the appropriate space. The possible range of scores for each section is provided on the final page. Each section total score is divided by the number of items to determine a more standardized score. Higher scores indicate greater needs. No cut off number to determine needs has been established at this time. Perhaps after the CFA tool has been used and modified further standardization may be possible and appropriate.

Note: This assessment is not comprehensive and individual agencies will need to conduct brief assessment to determine what specific services might be needed. Furthermore this assessment should not be completed only once. It should be repeated as deemed necessary by agencies involved with the family

COMMON FUNCTIONAL ASSESSMENT TOOL
Developed by Saskatoon Communities for Children

Date Completed

Completed by:

Name of Child/youth

Age of Child/ youth

Parent/Guardian

Rating Scale
1 = no burden,
2 = occasional difficulties,
3 = continual, but manageable difficulties,
4 = continual and sometimes unmanageable (need occasional support), and
5 = over burdened (need ongoing support).

A. PERSONAL CARE

1. Does the child have any special personal care needs including bathing, dressing, eating, grooming, or toilet training? Yes _____ No _____ (If no please skip to # 8). Multiply impact score by response number of question.

2. Bathing
   1) ____ no supervision /age appropriate (AA)
   2) ____ needs reminders
   3) ____ some assistance
   4) ____ bathed by caregiver
   5) ____ exceptional needs (e.g. 2 care givers)

Relative impact of needs _____

Comments: _____

_____Total_____

3. Dressing
   1) ____ no supervision/AA
   2) ____ needs reminders
   3) ____ some assistance
   4) ____ dressed by care giver
   5) ____ exceptional needs (e.g. adapted clothing)

Relative impact of needs _____

Comments: _____

_____Total_____

4. Eating
   1) ____ can cook own meals/age appropriate
   2) ____ no supervision/AA
   3) ____ some assistance (cooking or eating)
   4) ____ spoon fed by care giver
   5) ____ fed by care giver and eating difficulties (e.g. fluids only)
   6) ____ exceptional needs (e.g. unable to eat orally)

Relative impact of needs _____

Comments: _____

_____Total_____

5. Grooming (e.g. teeth brushed, wash hands)
   1) _____ no supervision/AA
   2) _____ reminders
   3) _____ some assistance
   4) _____ groomed by care giver
   5) _____ exceptional needs (e.g., resists)

Relative impact of needs_____

Comments: _____

_____Total_____

6. Toilet Training
   1) _____ toilet trained/AA
   2) _____ reminders
   3) _____ regular assistance
   4) _____ exceptional needs (e.g. catheterization)

Relative impact of needs _____

Comments: _____

_____Total_____

7a. Sleeping Habits
   1) _____ sleeps through the night/AA
   2) _____ trouble getting to sleep
   3) _____ does not sleep through the night
   4) _____ wakes during the night and wanders (e.g., sleep walking, in house alone)

Relative impact of needs_____

Comments: _____

_____Total_____

7b. In what ways does this family need additional support for personal care, if any?

7c. If the family needs support, what formal/informal resources would meet the family's needs?

7d. From where can the family access this support?

B. SENSORY/PHYSICAL

8. Does the child have any special sensory or physical needs including hearing, vision, communication, or mobility? Yes _____ No _____ (if no, please skip to # 17).

9. Hearing
   1) ____ no hearing difficulties/AA
   2) ____ difficulty with back ground noise
   3) ____ some modified communication assistance
   4) ____ always modified communication assistance
   5) ____ hears no sounds

Relative impact of needs _____

Comments: _____

_____Total_____

10. Does the child use hearing aids? ____ Yes ____ No

11. Vision
    1) ____ no vision difficulties/AA
    2) ____ wears glasses
    3) ____ minor environmental changes (e.g., large letters, bright colours)
    4) ____ needs assistance in unfamiliar environments
    5) ____ legally blind

Relative impact of needs _____

Comments: _____

_____Total_____

12. Does the child have any other sensory issues? Yes ___ No ___ Please explain.

13. How does the child communicate

a) ____ speaking

What language?
____ English
____ French
____ First Nations (which: _____)
____ other

b) ____ sign language

What type?
____ Signed English
____ American Sign Language
____ American Indian
____ other (which: _____)

c) ____ Symbols

d) Other (explain)

Relative impact of needs _____

Comments: _____

_____Total_____

14. What other communications needs does the child have? (e.g. speech therapy, stutter)

Relative impact of needs ____

15. Mobility
    1) ____ independent/AA
    2) ____ minimal assistance (e.g. on stairs)
    3) ____ independent in some settings (e.g. in wheelchair)
    4) ____ supervision and assistance
    5) ____ total assistance

Relative impact of needs _____

Comments: _____

_____Total_____

16a. In what ways does this family need additional support for sensory or physical issues?

16b. If the family needs support, what formal/informal resources would meet the family's needs?

16c. From where can the family access this support?

C. BEHAVIOURS

17. Does the child have any special behavioural needs that include environmental awareness, physical or verbal aggression, destruction, inappropriate activity level, repetitive, disruptive behaviours, or sexual behaviours, or social awareness? Yes _____ No _____ (if no please skip to # 28).

18. Environmental Awareness
    1) _____ interacts willingly with others/AA
    2) _____ aware of surroundings
    3) _____ partially aware of surroundings (reminders)
    4) _____ not aware of surroundings

Relative impact of needs _____

Comments: _____

_____Total_____

19. Physical Aggression
    1) _____ never physically aggressive with self/other/AA
    2) _____ infrequent aggression with self/other
    3) _____ frequent aggression—minor discomfort to self/other
    4) _____ frequent aggression—unintentional serious injury to self/other
    5) _____ frequent aggression—intentional serious injury self/other

Relative impact of needs_____

Comments: _____

_____Total_____

20. Verbal Aggression
    1) _____ never verbally aggressive/AA
    2) _____ infrequent verbal outbursts
    3) _____ frequent outbursts
    4) _____ frequent prolonged outbursts—intentional harm to others

Relative impact of needs ____

Comments: _____

_____Total_____

21. Destruction
    1) _____ never destructive/AA
    2) _____ accidental property damage (e.g. due to lack of coordination, high activity level)
    3) _____ major property damage from undirected outbursts
    4) _____ deliberate major damage

Relative impact of needs _____

Comments: _____

_____Total_____

22. Activity Level
    1) ____ appropriate to situation/AA
    2) ____ appropriate with reminders
    3) ____ constant fidgets or inactive
    4) ____ not on task with continual supervision/reminders

Relative impact of needs _____

Comments: _____

_____Total_____

23. Repetitive Behaviour
    1) ____ no behaviours interfere with activities/AA
    2) ____ behaviours not harmful or disruptive but stigmatized (e.g., sucking finger)
    3) ____ behaviours disrupt others' activities (e.g. talking loudly to self)
    4) ____ behaviours danger or health risk to self/others

Relative impact of needs _____

Comments: _____

_____Total_____

24. Disruptive Behaviour
    1) ____ no disruptive behaviours/AA
    2) ____ infrequent, easily managed behaviours
    3) ____ regular disruptive behaviours
    4) ____ behaviours that present danger to self/others

Relative impact of needs _____

Comments: _____

_____Total_____

25. Sexual Behaviour
    1) ____ understand and behaves accordingly/AA
    2) ____ sexual interest in immature/atypical ways
    3) ____ sexually unacceptable behaviour—requires supervision
    4) ____ high risk of sexual offending behaviour—supervision in all environments

Relative impact of needs _____

Comments: _____

_____Total_____

26. Social Awareness
    1) ____ aware of others' feelings, privacy, property/AA
    2) ____ unaware of others which interferes with social relations
    3) ____ offensive behaviour to acquaintances and strangers (e.g. insulting)
    4) ____ little or no regard for safety/well-being of others

Relative impact of needs _____

Comments: _____

_____Total_____

27a. In what ways does this family need additional support for behavioural issues?

27b. If the family needs support, what formal/informal resources would meet the family's needs?

27c. From where can the family access this support?

D. SAFETY

28. Please check off yes for items the child can and does do and no for those the child cannot or does not do. Also indicate for each whether the behaviour (or lack of) is age appropriate.

	Yes	No	AA	
1)	____	____	____	can use the telephone correctly
2)	____	____	____	can cross street unaided (looks both ways and crosses when no cars)
3)	____	____	____	can stay alone for short periods of time (less than 2 hours)
4)	____	____	____	can stay alone for most of one day
5)	____	____	____	can cook a simple meal for self (can use stove, microwave, toaster)
6)	____	____	____	knows phone number and can communicate to others
7)	____	____	____	knows own and parents' names and can communicate to others
8)	___	____	____	understands and follows instructions (e.g. do not talk to strangers)

Relative impact of needs _____

Comments: _____

_____Total_____

29a. In what ways does this family need additional support for Safety-related issues?

29b. If the family needs support, what formal/informal resources would meet the family's needs?

29c. From where can the family access this support?

E. HEALTH LEVEL

30. Maintenance
Please indicate whether the child needs or uses any of the following:

1) ____ Occupational Therapy
2) ____ Physical Therapy
3) ____ Speech Therapy
4) ____ Psychiatry
5) ____ Psychologist
6) ____ Other (please specify_____)

Comments: _____

_____

31. Medications
Please indicate a) what medications the child/youth takes, b) how the medications are administered, c) for what condition, and d) any known side effects (e.g. insulin—needle, twice a day for diabetes, nausea)?

32. Please list and describe the child's health care needs.

33. What is the weight of the child? _____

34. What is the height of the child? _____

35. Please describe the child's needs in terms of equipment and transfers.

36. What is the child's Intelligence Quotient (IQ) if known or the child's level of functioning (e.g. borderline deficit, mild deficit, moderate deficit, severe deficit, profound deficit)

F. FAMILY SUPPORT NEEDS

37. Where does the child live? In the blank following the options below please write how long the child has lived there.

1) _____ at home with parent(s) How long _____
2) _____ foster care How long _____
3) _____ group home How long _____
4) _____ with a relative How long _____
5) _____ other (please specify _____)

38. Please list all of the people who live in the home with the child.

To be answered by parent/family member. Please select the answer that best explains how you feel.

39. My family does not receive enough help from friends and family

1	2	3	4	5
strongly agree	agree	unsure	disagree	strongly disagree

40a. My family does not receive enough help from services in the community.

1	2	3	4	5
strongly agree	agree	unsure	disagree	strongly disagree

40b. What organizations are you involved with in Saskatoon (or Saskatchewan)related to your child's needs?

41. My family does not have enough money to meet our needs (including special needs of child)

1	2	3	4	5
strongly agree	agree	unsure	disagree	strongly disagree

42. What coping strategies do you use with your children?

43. Please describe the relationships among your family members.

44. What medical or psychological diagnoses, if any, does your child have?

F. Totals

Please review the responses and write the total score for each section. Multiply the relative importance by the number chosen for each question then add the results for each question in each section.

Personal Care _____ (min 7 max 170) divided by 7

Sensory Physical _____ (min 5 max 85) divided by 5

Behavioural _____ (min 8 max 165) divided by 8

Safety _____ (min 1 max 40)

Maintenance Comments _____

_____

_____

Family needs _____ (add 37, 38, 39) (Min 3 max 15) / 3

IQ or category _____

Diagnoses _____

Note: This page should be used as a summary and the child should not be assessed solely by this page. The numbers may not provide an accurate representation of the family situations of the child with disabilities. Do not create a composite score as the meaning of each measure will be lost.

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