



# Outcome Star™ Demonstration Project for the Central Alberta FASD Clinic

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## **Background**

This demonstration project will evaluate the effectiveness of the Outcome Star™, an outcomes measurement tool as it pertains to medical investigation within Fetal Alcohol Spectrum Disorders. This tool would be used to gather pre and post assessment information regarding individuals referred being evaluated through the Central Alberta Fetal Alcohol Spectrum Disorder (FASD) Clinic. The Clinic is in a very unique position, as the world is looking to Alberta as the leaders in assessment and diagnosis, there are not any clinics currently within Alberta or the world gathering outcomes in regards to assessment and diagnosis. The Outcome Star™ tool would be implemented as a pre measure prior to assessment and then at six and twelve months post assessment and diagnosis as a way to gather evidenced based data as to the benefit of assessment and diagnosis in terms of positive outcomes for the patients.

## **Why implement an outcome tool?**

Gomez, Arias, Verdugo & Navas (2011) explain “it is widely accepted that quality of life concept is important in social services to implement person-centered programs and practices, to assess and report personal outcomes, to guide quality improvement strategies, and to improve the effectiveness of those practices and strategies using evidence-based or outcomes-based measurements” (p. 81). Within the last ten years there has been a shift in Human Services to demonstrate that services are improving the lives of their clients, which in turn has a cost benefit to society.

Cerullo & Cooney (n.d.) explain “...performance measurement, with its focus on demonstrating effectiveness, has become deeply embedded in how policy makers and funders and service providers think about programs designed to illicit changes in human beings” (p. 365). The shift of funders requesting outcomes (achievement of goals) rather than outputs is what really matters when measuring the difference a service makes in the individuals accessing services.

MacKeith (2001) believes that it is useful for both policy makers and service providers to develop their understanding and identify best practices through evidence-based practice (p. 2). The literature strongly supports the value and importance of outcome measures in order to measure the benefits of a service. This then allows for identification of ways for service enhancement as well as shape person centered best practices.

Within Alberta there are 24 assessment clinics, the two clinics in existence for approximately twelve years. There are more clinics in Alberta than there are in all the provinces in Canada. Many countries in the world do not yet have a single clinic specific to FASD evaluation. It is for this reason that Alberta is a world leader in screening and diagnosis of FASD. Assessment of adults in particular is still a relatively new field with little existing research related to adult assessment and diagnosis particularly in post assessment outcomes.

The Central Alberta FASD Clinic has been in operation for just over 3 years, having assessed approximately 100 individuals, primarily adults (18 years and over). Clearly, assessment and

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diagnosis has a positive impact on patient's lives. We have seen firsthand the beneficial changes that have occurred. For example we assessed a man in his mid 30's who was referred to us by his Parole officer. His history revealed that he had spent the majority of his adult life in custody. He had over 36 armed robbery charges all of which he carried out under the influence of drugs and alcohol. The longest period he had been out of jail was nine months before reoffending. The FASD assessed him approximately two years ago (2012), Currently today he has been employed for two years, is no longer on parole, has maintained sobriety from drugs and alcohol, secured housing and AISH funding. These life changing outcomes were the result of him obtaining an FASD assessment. Once a comprehensive, multidisciplinary assessment was completed the clinic team was able to identify his strengths, learning style, areas where he needed support and were able to identify what supports he would qualify for. Due to his diagnosis he was able to access ongoing FASD Outreach support, and receive AISH. His employer and Parole officer were then able to understand how to best support him. Once they understood his functioning there were then able to have appropriate expectations of him to help set him up for success rather than failure. This gentleman was part of our international FASD Day in September where he spoke about his experiences and how an assessment positively changed his life. This is only one of many individuals that have had life changing experiences post diagnosis. This is the impetus for measuring outcomes using the Star Outcome™ tool.

Frame (2003) explains "that a need emerges and is recognized, and then the management determines whether the need is worth fulfilling. If it is, then a project is organized to satisfy the need" (p. 112). I believe there is clear need for the FASD Clinic to move forward in piloting an outcomes tool.

The challenge then becomes finding a tool that can measure patient growth while gathering data to prove change and benefits. Developers of the Outcome star Burns & MacKeith (2012) describe this tool as a new approach

to assessment and outcomes measurement. The Star approach can be described as Participatory Assessment and Measurement (PAM) because it draws on and extends Action Research and Participatory Action Research (PAR), both of which place empowerment, collaboration and integration at the core research methods. In the same way, the Outcomes Star seeks to empower people within a collaborative process of assessment and measurement that is integrated with support work, rather than a separate activity. (p. 7)

## **Outcome Star™**

The Outcome Star was developed by Sara Burns and Joy MacKeith (2012) in the UK as a way to measure change when working with people. The first star was developed to use with the homeless population. There are now 17 different stars which include stars for addictions, families, mental health and the star that the demonstration project will use – the Life Star. The Life Star was developed to work with individuals with learning disabilities which would include cognitive impairment. It is for this reason the Life Star was chosen as the best fit for this demonstration project.

Burns & MacKeith (2012) explain how the life star "enables organisations to measure and summarize the changes made by the people using your services. It is also a keywork tool that can

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support service users and staff to work together to maximize the service user's independence, choice and wellbeing. It does this by providing them both with a clear picture of the steps on the journey and of their progress" (p. 4).

The Life star looks at ten areas that have been identified as essential for individuals with learning/cognitive disabilities to work towards independence and well-being:

1. Your health
2. How to spend your time
3. Being responsible
4. Being safe
5. Money and letters
6. Living skills
7. Communication
8. Feeling good
9. People you know
10. Mental health and other conditions

Each area creates an arm on the star with there being a ten point score on each arm of the star indentifying where the individual is on their journey towards independence, choice and wellbeing in that area. The score is developed around the understanding of the model of change.

## **Reasons for introducing the Outcome Star**

### **Internal reasons:**

- The underpinning values of the tool match the core values of the Central Alberta FASD Clinic when working with patients and their families/caregivers.
- The Central Alberta Network has recently hired three new employees. This tool will help to reinforce the values and beliefs that the Central Alberta FASD Network hold while giving the staff a functional tool to use when supporting individuals through the Network.
- To create a common language between FASD Clinic Team, stakeholders and collaborative community services.
- To further develop clinic and follow up procedures to better meet the needs of our patients and their families/caregivers
- To create best practices, based on evidence based data, to enhance support to patients and their families/caregivers.
- To establish a best practice standard that can be adopted by FASD Diagnostic Clinics worldwide.

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## External reasons:

- To demonstrate to the Cross Ministry Committee (CMC) and to the global FASD diagnostic community the potential favourable impact of assessment and diagnosis as indicated by evaluation of patient outcomes using the Star Outcome™ tool.
- To demonstrate that both fiscal and human costs related to this disability can be reduced through FASD assessment and diagnosis which identifies and promotes appropriate patient-specific supports for the individual.

## Suitability of the Outcome Star™ with the Clinic

- The Clinic works collaboratively with many community agencies and government programs in developing support and services plans for patients who have gone through the assessment. This supports and services plan identifies the different formal and informal supports that are part of the patient's team. As well as identifies who is doing what role and who is responsible for completing tasks and clinic recommendations. This case conference develops "the road map" in helping the patient and their family move forward in achieving the clinic recommendations, accessing supports, moving patients forward in achieving their goals, and working towards independence in an appropriate and supported manner.
- The journey of change that the Outcome Star™ is developed around parallels how Network staff and FASD community supports works with the patient/client. In working towards independence, in a patient centered way starting where the patient is at in terms of readiness to make changes and work on goals.
- Most of the patients we see are not capable of maintaining complete independence without supports and services over the lifespan. That is why identifying appropriate expectations for each individual patient is critical in order to then set up appropriate supports for each individual's situation in a way that fosters success.
- Many patients seen at the FASD clinic process and follow up is critical. We work hard to show the patient that the clinic process is happening with them as opposed to them.

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## **Demonstration Project**

### **Initiating Phase**

The Central Alberta FASD Clinic will run a demonstration project to determine if the Outcome Star is a useful/beneficial tool and should therefore become a regular part of the global diagnostic clinic process.

Questions for review in determining the suitability of the Outcome Star™ being adapted to the Central Alberta FASD Clinic's procedure:

1. How much time would the tool add to staff's workload/responsibilities?
2. What is the worker's attitude in regards to using the tool? (To measure this a pre and post questionnaire rating on a 5 point Likert scale will be used for workers to complete prior to launch and at the end of the project to measure various points)
3. What was the patients attitude regarding the use of the tool? (To measure this a survey will be developed to have the patient complete after they used the star to gather information about the patients' experience with the tool)
4. Did the caregivers find this tool helpful in increasing their knowledge of what services existed? As well as how to access the services in order to support their individual living with an FASD along with other caregiver outcomes as identified by FASD-CMC Strategic and Operational Plan 2013-2014 (Measured by a questionnaire).
5. Does the tool meet our needs for measuring outcomes with patients going through assessment and diagnosis?
6. Did the tool increase collaboration between service providers? (This will be measured with a questionnaire that will be completed by service providers participating in the supports and services case planning meeting)
7. Does the tool fit with the CMC plans to develop a data collective model?
8. Did the tool enhance clinic recommendations? If so, how?
9. Does the tool fit with our clinic's values and philosophies?
10. Does it make sense to complete the tool at six and twelve months post clinic, or is it best to just complete it at twelve months post clinic?
11. What would be the best way to interpret the data and how should the data be used?
12. Does the tool increase patients and caregivers understanding of supports and services available to them in their community, and are they referred to the post-assessment supports needed (FASD-CMC," 2013 p.38)?

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13. Can the tool enhance “Data collection based on intake and interviews and regular client progress interviews (“FASD-CMC,” 2013, p. 39)”?
14. Can this tool demonstrate improvement in well being for patients diagnosed or suspected of FASD? (“FASD-CMC,” 2013, p. 39)
15. Can this tool increase well being for caregivers? (“FASD-CMC,” 2013, p. 40)
16. Can this tool act as a mechanism to increase stakeholder engagement and collaboration by creating a common language? (“FASD-CMC” 2013, p.40)
17. How can this tool inform research to better enhance FASD programs and services? (“FASD-CMC,” 2013, p. 42)

## **Key Stakeholders**

The Central Alberta FASD Network recognizes that the work we do with individuals and their families/caregivers is in close collaboration with many different programs and services. This is essential in order to meet the needs of often complex challenges and needs of the individuals and their families/caregivers.

For the purpose of this demonstration project we would have the following partners trained and with their consent participate in this project. The partners are as follows:

- Central Alberta FASD Network staff – Central Alberta FASD Network Coordinator, Central Alberta FASD Diagnostic Coordinator, Clinic Assistant and the FASD Corrections Assistant.
- Parent Child Assistance Program (PCAP) – Mentors
- Catholic Social Services FASD Outreach Program – FASD Outreach Worker
- McMan FASD Outreach Program – FASD Outreach Workers and Supervisor
- South Central FASD – Outreach Worker

The scope of this project would be to complete the outcome star™ with all patients starting the assessment process (from the date of launch with their consent). If the patient is within the corrections system and is incarcerated then the Corrections Assistant would complete the tool with them. If a patient is being referred by the Parent Child Assistance Program or FASD Outreach, the worker with whom there is a relationship would complete the tool with them. If the patient is not attached to a program then the Clinic Assistant/Clinic Coordinator will complete the tool with them. The tool will be incorporated into the intake process for patients.

The six and twelve month follow up will be done by the same worker that completed the tool with them at the point of intake. If this is not possible then the Clinic Assistant/Clinic

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Coordinator will complete the tool. The Clinic Assistant and Corrections Assistant are two new roles within our clinic and part of their role is to do a 3, 6, and 12 month follow up with the patients following the assessment, to ensure that everything is still on track with following through with the clinic recommendations, working on the patients goals and the supports in their life and ensuring all supports are still on the same page.

### Launch date of project

May 1, 2014 – begin completing outcome star with patients going through an assessment  
 Dec 31, 2014 – stop completing outcome star with patients going through an assessment

This period of 7 months will include 6 assessment cycles of 5-6 patients per cycle for a total of 30-36 patients within this time frame.

Assessments completed by	6 month review	12 month review
June 2014	Dec 2014,	June 2015
Sept 2014	Mar 2015	Sept 2015
Dec 2014	June 2015	Dec 2015

### Planning Phase

The Team	Roles
Trina Kennedy RSW Clinic Coordinator	project lead, to oversee the implementation of the tool through the clinic process, supervise the clinic assistants in regards to implementation of the tool with patients, provide support for community agencies using the tool with their clients, complete tool with some patients to gain firsthand experience with the tool
Betty Lou Benson Central Alberta FASD Network Coordinator	approve budget costs, oversee the project budget, explore funding options for the demonstration project
Raymond Downie, Ph.D. Outcome Star Trainer Broadview Applied Research Group Inc.	train the team in the Outcome Star, consultation regarding the application of the tool such as ensuring consistent application, fidelity of data and inter-rater reliability, data management, aggregation and analysis of results – both process and outcomes, preparation of the evaluative report both implementation matters and outcomes achieved (interim 6 months and final report)

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<b>Vicki Gassor B.A. Psyc FASD Clinic Assistant</b>	to complete the tool at intake and at 6, 12 month post assessment, provide feedback regarding what is working, what is not working and how we could make things better, additional project duties as given by Clinic Coordinator
<b>Garett Hingst RSW FASD Corrections Assistant</b>	to complete the tool at intake and at 6, 12 month post assessment with individuals incarcerated or in the justice system, provide feedback regarding what is working, what is not working and how we could make things better
<b>FASD Outreach Workers (Mcman, CSS and Southcentral) Total of 5 outreach workers</b>	to complete the tool with any of their clients that are going through an assessment at intake and at 6, 12 month post assessment, provide feedback regarding what is working, what is not working and how we could make things better

### Budget

Project Costs	Total Actual	Total Budget
Outcome Star Training A day and a half (Star materials included)	\$3600.00	\$5900.00
Travel/accommodations	0000	
Food for training/team meetings		\$200.00
Ongoing training, data management, report writing (this includes all licensing fees)		\$35,000.00
Travel and related expenses		\$5000.00
<b>TOTAL</b>		

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## Project Plan

Tasks	Date to be completed by	Who is responsible for completing
Explore training options and costs for training	Jan 25/14	BL
Meet with Trainer to discuss the tool and training	Jan 30/14	BL
Schedule and organize training	Feb 5/14	BL
Identify team and roles of team members	Feb 5/14	Trina
Complete team training	Feb 24 and 25	Entire team
Develop demonstration project plan	Mar 10/14	Trina
Meet with entire team to discuss rolling out the tool, launch date, indentify potential challenges and ideas how to work around the potential challenges	Mar 17/14	Entire team (except Raymond)
Develop partner contract outlining commitment, roles and responsibilities in participating	Apr 1/14	Trina
Develop a excel spreadsheet to input data	Apr 1/14	Trina, BL and Ray
Develop pre and post measures to be used as part of the project	Apr 1/14	Trina and Vicki
Get commitment from partners as to participation or not	Apr 15/14	Trina
Launch the use of the tool with patients through the clinic and community programs	May 1/14	Clinic and Corrections assistant, community workers
Have a team meeting to discuss how the use of the tool has gone. Discussion about any challenges with the tool, suggestions of what team has found helpful or beneficial. Problems solve any challenges.	Jun 1/14	Entire team
After a full clinic cycle has been complete have a project meeting to evaluate how the process went, make any required changes and tweak the process if required	Sept 5/14	Individuals that completed the tool with patients to this point
Team meeting to review progress of project to date	Oct 15/14	Entire team
Have team complete the post questionnaire as to their experience with the tool.	Jan 15/15	All who used the tool with patients/clients

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Review goals and questions to be answered other than the data specific questions. To determine implementation of tool throughout clinic	Jan 30/15	All who were involved in using the tool
Have a celebration for the project team to celebrate and thank everyone for their participation in the project	Feb1/15	Entire team
Communicate decision, benefits, learnings and challenges within this demonstration project and if applicable how the tool will be rolled out and how challenges will be addressed	Feb 15/15	Trina
Identify needed clinic policies and procedures to roll out as standard practice for clinic	Mar 1/15	Trina
Review first round of 6 month reviews as they come in	March- May/15	Trina
Write interim report after 6 month review	June 1/15	Ray
Communicate results from first round of reviews to the team	June/15	Trina
Team meeting to review how clinic wide implications have gone to date and discuss success and challenges	June 1/15	All who have used the tool with patients/clients to date
Review second round of 12 month reviews data	Sep – Nov/15	Trina, BL and Ray
Write evaluation report following wrap up of project	Jan/16	Ray
Communicate results from second round of reviews to the team and share with the CMC	Jan/16	Trina, BL

### Potential Challenges

In order to be proactive it is important to try and anticipate potential challenges that could interrupt the progress of the project. Potential challenges and solutions are as follows:

**Loss of workers that are trained in the tool** – If we lose trained workers there are clinic staff that could complete the star review. However, this is not ideal due to interrelated reliability of the tool.

**Interrelated reliability issues** – To minimize this potential there will be regular team meetings throughout the project. These meetings will be used to do case examples to ensure everyone interprets the case information the same way. Ensuring that workers are using the note section to clearly document why each area was given that rating in case a different worker has to do the review there will be good information about the last time the tool was completed with the patient.

Team meetings will also allow for team sharing as to discussing challenges they may have had with the tool and team problem solving as to what a good solution may be.

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Ongoing support and check-ins will occur with the workers completing the tool to answer questions and ensure understanding.

**Budget limitations** – securing funding to support this demonstration project will be explored but will be a limitation if there are no funding sources secured.

## **Implications of the project**

Can this tool create a new and innovative approach to case management and achieve client/caregiver outcomes collaboratively? Does this tool gather evidence that will help to demonstrate achievement of provincial outcomes? Did this project identify promising practices and implementation challenges that can assist others in implementing similar outcome measurement approaches and replicating the efforts of the Central Alberta Network?

## **Learning's from the project**

What was learnt in the process of this demonstration project? What were the barriers and challenges in implementing this project or tool? How were the challenges and barriers resolved? What went well with this project? What would we recommend to do differently in order to reduce the barriers? How did the utilization of this tool improve and/or enhance collection and reporting of outcomes, as identified in the 2013-3014 FASD-CMC Strategic and Operational Plan?

Alberta is the leader in assessment and diagnosis. In order to continue to be at the forefront it will be important to demonstrate with quantitative data the positive results of assessment and diagnosis. We hope that the CMC will see the value of the demonstration project and partner with the Central Alberta FASD Network in funding this project. Thank you for your consideration.

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