



## Enhancing the social connectedness of mothers with intellectual impairment

Alberta pilot of the Supported Learning Program

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## **LAY SUMMARY**

### **Background**

Mothers with intellectual impairment tend to have smaller social networks and report lower levels of social support than other mothers. This social isolation is linked to higher levels of maternal stress, anxiety and depression, and in turn, poor child outcomes. The Supported Learning Program (SLP) is a flexible, group-based program designed to strengthen the social relationships and improve the psychological wellbeing of mothers with intellectual impairment. The aim of this study was to trial the SLP in Alberta.

### **Method**

The SLP was trialed in two rural and two urban locations, and involved a total of 33 mothers with intellectual impairment. Evaluation included pre and post-test measures of psychosocial well-being, goal attainment scaling, and interviews with SLP facilitators and participants.

### **Key Findings**

Despite the considerable effort involved in getting the mothers into the program and sustaining their participation, the clear consensus among SLP facilitators was that “it is worth the effort”. SLP participants reported a high level of goal achievement and a meaningful reduction in depression, anxiety and stress symptoms. For the participants, the most significant outcome of the SLP may have been the discovery that they were not alone; other mothers struggled too, and felt much the same way they did - flawed and fearful.

### **Conclusions**

People who experience prolonged social isolation tend to view the world as a more threatening place, and expect more negative social interactions. Consequently, it can be difficult to convince them that participating in a group-based program is safe. However, once the mothers discovered that they were not alone, and would not be judged (i.e., it was safe), participating in the group phase gave them something to look forward to each week, opportunities to learn and support others, and a feeling of “being a part of society”.

### **Recommendations**

- 1) Family support workers and FASD workers across the province of Alberta should consider collaborating to offer the SLP to mothers with intellectual impairment.
- 2) Agencies/workers who implement the SLP should encourage such groups to evolve into continuing Self Advocacy groups, where new friendships could be made and maintained, and members could continue to support and learn from one another as they strive to achieve their long term goals.

## EXECUTIVE SUMMARY

- Mothers with intellectual impairment tend to have smaller social networks and report lower levels of social support than other mothers. This social disconnection is associated with higher levels of maternal stress, anxiety and depression, and in turn, adverse parenting and child outcomes.
- The Supported Learning Program (SLP) is a group-based intervention supplemented by individual support, which is designed to strengthen the social connections and enhance the psychological well-being of mothers with intellectual impairment, with concomitant benefits to their children.
- The SLP employs a problem-posing approach to adult learning, based on the work of educational philosopher Paulo Freire (1993, 1998), to build the awareness and confidence of mothers with intellectual impairment to ‘get out and about’, and be in their community.
- To evaluate the SLP, a multi-site, within-subjects, pre-test post-test trial was undertaken. To obtain rich process and outcome data, the evaluation incorporated measures of psychosocial well-being, goal attainment scaling, and interviews with SLP facilitators and participants.

### *Participant Profile*

- The SLP was implemented in four locations, including two rural and two urban locations. In both rural locations, generic family support service workers and FASD (Parent Child Assistance Program [PCAP]) services workers collaborated to implement the SLP.
- A total of 33 mothers with intellectual impairment agreed to participate and completed the pre-group phase of the SLP. Of these, 18 mothers completed all phases of the SLP. Most of the mothers (13 of 15) who did not complete the group-phase of the SLP were recruited by the urban sites.
- The majority of participants were aboriginal. Approximately two-thirds were single mothers. Few had graduated high school, and most were dependent on disability income support (i.e., AISH). Most had a dual diagnosis of intellectual impairment and substance abuse/addictive disorder.

### *Selected Findings*

- Despite the considerable effort involved in getting the mothers into the program and sustaining their participation, the clear consensus among SLP facilitators was that “it is worth the effort”. Facilitators described their experience of the SLP in terms such as “eye-opening”, “amazing” and “fantastic”.
- Participation in the SLP was associated with a meaningful reduction in participant depression, anxiety and stress symptoms. The effect sizes ranged from 0.57 for depression to 0.71 for anxiety. These are larger than those typically reported for generic parenting/ family support programs.
- The mothers who completed the SLP reported a high level of goal achievement including, for example, making new friends, learning strategies for handling difficult social situations, and feeling more confident about participating in groups and going places in their community.

- For the participants, the most significant outcome of the SLP may have been the discovery that they were not alone: other mothers struggled too, and felt much the same way they did, namely, flawed and fearful. In a group with experientially similar others, the mothers not only felt understood and accepted, they also felt like they had something valuable to contribute.
- Each week, SLP participants are asked to identify the barriers, for example, to utilising community resources (e.g., leisure and learning facilities) or becoming more involved in their community through volunteering. When the same barrier (i.e., the mothers' fearful perception) was identified, week after week, the discussion and homework activities were perceived by some as repetitious.

#### *What worked well?*

- The collaboration and complimentary expertise of generic family support service workers and FASD (i.e., PCAP) service workers worked well. This was effective in engaging and sustaining the participation of the mothers in the SLP.
- Bringing experientially similar mothers together, and 'trusting the group process' worked well. Trusting the group process meant resisting the urge to instruct (as opposed to facilitate): "letting [the mothers] be themselves... letting them experience getting into a group and finding their way".
- SLP facilitators valued the flexibility of the SLP. This enabled SLP facilitators and participants to 'own the program', innovating and adapting it according to their needs, strengths and interests, while staying true to the core principles and processes.

#### *What did not work so well?*

- The participants did not find the homework component of the SLP, which is contained in a Participant Workbook, very helpful. Moreover, the participant workbooks were frequently misplaced. One of the SLP sites adapted by completing the homework activities in-group, and storing the participants' workbooks on-site.

#### *Conclusion and recommendations*

- Implementing the SLP is an inherently demanding undertaking. People who experience prolonged social isolation tend to view the world as a more threatening place, and expect more negative social interactions. Consequently, it can be difficult to convince them that participating in a group-based program is safe. However,
- Once the mothers with intellectual impairment who took part in the SLP discovered that they were not alone, and would not be judged (i.e., it was safe), participating in the group phase gave them something to look forward to each week, opportunities to learn and support others, and the feeling of "being a part of society".
- The recommendations are: (1) family support (Parent Link Centre) workers and PCAP workers across the province of Alberta should consider collaborating to offer the SLP to mothers with intellectual impairment as an adjunct to other services; and, (2) agencies/workers who implement the SLP should consider how opportunity could be created for the time delimited SLP group to evolve into a continuing Self Advocacy group, where new friendships could be made and maintained, and members could continue to support and learn from one another as they strive to achieve their long term goals.

Mothers with intellectual impairment<sup>1</sup> typically have smaller social networks, report lower levels of social support, and participate less in the community than their non-disabled peers (Araujo & Aiello, 2013; Feldman, Varghese, Ramsay & Rajska, 2002; Llewellyn & McConnell, 2002; Llewellyn, McConnell, & Bye, 1998; Stenfert-Kroese, Hussein, Clifford, & Ahmed, 2002; Walton-Allen & Feldman, 1991). This social disconnection is associated with heightened levels of stress, anxiety and depression and, in turn, adverse parenting and child outcomes (Aunos, Goupil, & Feldman, 2004; Aunos, Feldman, & Goupil, 2008; Feldman, Varghese, Ramsay, & Rajska, 2002; McConnell, Mayes, & Llewellyn, 2008a; Wade, Llewellyn, & Matthews, 2011; Willems, de Vries, Isarin, & Reinders, 2007). The purpose of this study was to conduct a preliminary trial of a group-based intervention that is new to Alberta, the Supported Learning Program (SLP), which is designed to promote the social connectedness and improve the psychological well-being of mothers with intellectual impairment.

## **BACKGROUND**

There has been sustained research attention given to the topic of parents and parenting with intellectual impairment since the 1940s. Researchers have employed diverse systems for classifying and identifying parents with intellectual impairment, in line with practices in their country of origin, yet the findings from this body of research are remarkably consistent. One consistent finding is that, above an intelligence quotient (IQ) of 60, parental IQ is not strongly associated with parenting competence (Booth &

Booth, 1993; Dowdney & Skuse, 1993; Tymchuk & Feldman, 1991). Notwithstanding, without appropriate support, children of parents with intellectual impairment are at increased risk for accidental injury and serious illness, developmental delay, learning difficulties and behavior problems (Feldman & Walton-Allen, 1997; Keltner, Wise, & Taylor, 1999; McConnell, Llewellyn, Mayes, Russo, & Honey, 2003). Further, international studies have found that children of parents with intellectual impairment are more likely than any other group (e.g., children of parents with mental illness) to be apprehended by child and youth protection authorities and placed permanently out-of-home. A recent analysis of the Canadian Incidence Study of Reported Child Abuse and Neglect, for example, found that 27.3% of all child welfare court applications concern children of parents with intellectual impairment (McConnell, Feldman, Aunos & Prasad, 2010).

There are multiple determinants of poor outcomes for parents with intellectual impairment and their children. Behavior-genetic studies show that general cognitive ability, typically indexed by a total score on a standardized intelligence test, is approximately 50% heritable (Plomin, 1999; Simonoff, Bolton & Rutter, 1996). Inherited risk may be compounded by poor pregnancy and birth outcomes. One Australian prospective birth cohort study found that the odds of preeclampsia were 2.85 times higher for pregnant women with intellectual impairment, and the odds of low birth weight and admission to neonatal intensive care were, respectively, 3.09 and 2.51 times higher for their children (McConnell, Mayes, & Llewellyn, 2008b). Birth registry studies in Sweden and the United States have obtained similar results (Hoglund, Lindgren & Larsson, 2012; Parish, Mitra, Son, Bonardi & Swoboda, 2014). Parents with

<sup>1</sup> Intellectual impairment, as it is used here, is synonymous with other terms used in the literature such as (mostly mild or borderline) intellectual disability, low general cognitive ability, cognitive impairment, and learning difficulties.



intellectual impairment and their children also face multiple psychosocial risk conditions. These include family poverty, social isolation, neighborhood deprivation, and chronically poor parent health, including but not limited to higher than population levels of depression, anxiety and stress (Llewellyn & McConnell, 2002; McConnell, Llewellyn & Bye, 1997; McGaw, 2000; Tymchuk, 1999).

### *Psychosocial risk*

Mothers with intellectual impairment tend to be more socially isolated, report lower levels of social support, and participate less in the community than other mothers (Baum & Burns, 2007; Darbyshire & Kroese, 2012; Llewellyn & McConnell, 2002; McGaw, Ball & Clark, 2002). As a group, these mothers also report higher levels of stress and generally poorer mental health (Feldman, Léger & Walton-Allen, 1997; Llewellyn, McConnell & Mayes, 2003; McGaw, Shaw & Beckley, 2007; Tymchuk, 1994). In what is widely regarded as the first scientific paper on the topic, Mickelson (1947) found that poor mental health was prevalent in a sample of 90 “feeble-minded” mothers, and was a primary influence on the quality of care given to their children. More than fifty years later, Llewellyn, McConnell and Mayes (2003) investigated the self-reported mental health status of mothers with intellectual impairment and compared this to Australian norms on the MOS Short Form (SF-36) health status questionnaire. Stratified by socio-economic status, they found that mothers with intellectual impairment reported significantly poorer mental health than women without intellectual impairment.

More recent research has established a link between the social connectedness of mothers with intellectual impairment, their mental health, and parenting and child outcomes. In a prospective birth

cohort study, McConnell, Llewellyn and Mayes (2008b) found high levels of depression, anxiety and stress among pregnant women with intellectual impairment associated with low levels of perceived social support. In a sample of Canadian mothers with intellectual impairment, Feldman et al. (2002) found a correlation between perceived social support and maternal stress, and in turn, Aunos et al. (2004) and Aunos et al. (2008) report significant correlations between maternal stress, parenting style and child behavior problems in this population. More recently, Wade et al. (2011) modelled contextual influences on the parenting practices of 120 parents with intellectual impairment and the well-being of their children. The study found that positive parenting practices and child well-being were more strongly associated with parent access to social support than with parent socioeconomic position and mental health. Feldman, McConnell and Aunos (2012) also modeled contextual influences on outcomes for children of parents with intellectual impairment. Utilising secondary data from a child protection sample of over 1000 children, this study found that low parental social support was associated with poorer developmental and behavioural outcomes.

In other population groups, maternal social disconnection has been linked to perinatal complications (Chou, Avant, Kuo, & Fetzer, 2008; Collins, Dunkel-Schetter, Lobel, & Scrimshaw, 2004; Ghosh, Wilhelm, Dunkel-Schetter, Lombardi, & Ritz, 2010; Nylén, O'Hara, & Engeldinger, 2013); low birth weight and fetal growth (Collins et al., 2004; Feeley, Gottlieb, & Zelkowitz, 2005; Feldman, Dunkel-Schetter, Sandman & Wadhwa, 2000; Giesbrecht et al., 2013; Nkansah-Amankra, Dhawain, Hussey, & Luchok, 2010); pre and post-natal depression (Collins et al., 2004; Dennis, 2010; Dennis et al.,

2009; Dennis & Letourneau, 2007; Diaz, Le, Cooper, & Munoz, 2007; Emmanuel, St John, & Sun, 2012; Haslam, Pakenham, & Smith, 2006; Honikman, 2008; McConnell et al., 2009; Sheng, Le, & Perry, 2010; Saias, Greacen, Brengard, Lejoyeux, & Bourdais, 2008); high parenting stress (Callahan & Borja, 2008; Feldman et al., 2002; Stenfert Kroese et al., 2002); low maternal warmth and responsiveness (Crouch, 2002; Feldman et al., 2002); insecure attachment relationships (Emery, Paquette, & Bigras, 2008; Huth-Bocks, 2003; Jacobson & Frye, 1991); heightened risk of child abuse and neglect (Bishop & Leadbeater, 1999; Kotch, Browne, Dufort & Winsor, 1999; Lyons, Henly, & Schuerman, 2005; Wandersman & Nation, 1998); and delays in child cognitive, emotional and social development (McManus & Poehlmann, 2012; Melson, Ladd & Hsu, 1993; Pianta & Ball, 1993; Sameroff, Seifer, Baldwin & Baldwin, 1993; Sohr-Preston & Scaramella, 2006; Slykerman et al., 2005).

### *Processes underlying social disconnection*

Processes underlying the social disconnection of mothers with intellectual impairment have received little research attention. Notwithstanding, many mothers with intellectual impairment were exposed to maltreatment in their own upbringing, and this is a strong predictor of social disconnection (Alink, Cicchetti, Kim, & Rogosch, 2012; Araujo & Aiello, 2013; Fisher, Moskowitz, & Hodapp, 2012; Hickson, Khemka, Golden, & Chatzistyli, 2008; Sperry & Widom, 2013). Secondly, most mothers with intellectual impairment have lived their lives 'under the microscope', and the perceived threat of negative social evaluation may cause them to withdraw from social interaction and relationships (Abbott & McConkey, 2006; Cacioppo, Hawkey, Norman & Berntson, 2011; Welsby & Horsfall, 2011).

Thirdly, most mothers with intellectual impairment have to contend with poverty, and many live in deprived and/or unsafe neighborhoods, which are both known risk factors for social isolation (Anderson et al., 2013; Ehlers-Flint, 2002; Emerson, 2007; Klebanov, Brooks-Gunn & Duncan, 2007). Further, mothers with intellectual impairment are more likely than their peers to suffer poor physical and mental health (including depression, anxiety and stress), which are both causes and consequences of tenuous social relationships (Aunos, Feldman, & Goupil, 2008; Emerson & Hatton, 2008; Gilmore & Cuskelly, 2014; Kroese, Hussein, Clifford, & Ahmed, 2002; Llewellyn, McConnell & Mayes, 2003).

### *Development of the Supported Learning Program*

Despite more than a decade of research documenting psychosocial risk for mothers with intellectual impairment and their children, intervention studies have continued to focus almost exclusively on parenting knowledge and skills. There is now unequivocal evidence that parents with intellectual impairment can learn parenting skills with appropriate instruction. Experimental and quasi-experimental trials have consistently demonstrated positive gains across a range of parenting skills including basic childcare, recognizing and responding in an appropriate and timely way to symptoms of childhood illness, and parent-child interaction and play (e.g. Feldman et al., 1989; Keltner, Finn & Shearer, 1995; Llewellyn, McConnell, Honey, Mayes & Russo, 2003; Tymchuk, Andron & Hagelstein, 1992). Few studies to date however have investigated the efficacy of interventions targeting psychosocial risk among mothers with intellectual impairment. A reasonable conclusion is that we now know a great deal about how to effectively teach parenting skills to parents with intellectual impairment, but we know very little

about how to address their social isolation, depression, anxiety and stress, which remain significant risk factors for adverse parenting and child outcomes. The Supported Learning Program (SLP) was developed to address this need for an intervention to reduce psychosocial risk among mothers with intellectual impairment and their children (McConnell et al., 2009).

The SLP is designed to address the nexus between social connectedness, psychological well-being, and maternal-child interactions. The SLP employs a problem-posing approach to adult learning, based on the work of educational philosopher Paulo Freire (1993, 1998), to build the awareness and confidence of mothers with intellectual impairment to 'get out and about', and be in their community. It comprises a flexible twelve-week group-work program supplemented by individual support (i.e., phone contact and home visits). The program is laid out in the Facilitator's Guide and Participant Workbook. There are three phases to the SLP:

- In the pre-group phase, the SLP facilitator will meet with participating mothers individually to discuss the group work program and set program-specific personal goals.
- The group-work phase includes weekly group meetings, each approximately three hours in duration, over 8-10 weeks. During this phase, participants will also receive individual support as they work on their personal goals.
- In the post-group phase the SLP facilitator will meet with each mother to review her progress toward achieving her personal goals.

The group-work phase of the SLP includes focused group activities, discussion and community

outings. Each week focuses on a different topic including, for example, 'places for children and families', and 'participating in my community through volunteering'. There is no curriculum of skills to be learned or information to be imparted by an expert. The awareness and confidence of participants is raised through an iterative process of critical reflection on their own experiences and working together and with the facilitator to plan a course of action to achieve their goals, and then putting those plans into action. During the group-work phase participants also complete weekly 'home challenges', which are contained in the Participant Workbook, and are designed to reinforce learning and to encourage further reflection and internalization of strategies for negotiating the community as a mother with intellectual impairment.

The SLP employs three main devices to facilitate this process. The first is the creation of a discussion object. Freire (1998) proposes creating discussion objects that he refers to as 'codes' or 'codifications' to give focus to a problem-posing dialogue. A code is a concrete physical representation of an issue in any form, for example, a role play, photos, collage, etc. Each code re-presents the community back to discussion participants. It enables them to project their emotional and social responses into the object for a focused discussion. In the SLP, group participants create a mural of their community. This mural is used throughout the group-work program as a discussion object. The mural represents specific places of interest or challenge to participants in a tangible way through the use of pictorial representations such as photos, drawings, and clippings. In each session, the participants place a photograph or image of themselves on different parts of the mural to indicate, for example, places in the community

that made them feel either secure and happy, or uncomfortable and threatened.

The second device is a three-step questioning strategy that moves the dialogue forward from description to reflection and then to problem solving. The first question calls for description: Participants are invited to share their experiences, to describe what happened, when and where. Common or shared experiences are identified. The second question elicits critical reflection: Participants are asked to consider 'why does this happen?' The third question moves the dialogue forward to planning and action: Together, participants identify strategies to overcome obstacles to social participation and achieve their goals. The process of developing a strategy of action is facilitated by the third device, a 'stepping stones' activity. The purpose of this activity is to break down a strategy for action into concrete, feasible steps. Together the mothers identify steps they can take to overcome constraints, and these are written down on 'stepping stones'. Placed in sequence, these stepping stones create a metaphorical pathway to fuller involvement and participation in their community.

#### *Promising preliminary data*

A multi-site, within-subjects, pretest post-test design was employed to pilot the SLP in Australia (McConnell, Dalziel, Llewellyn, Laidlaw & Hindmarsh, 2008). There were six pilot sites, including two in urban areas and four in rural areas. At two sites the SLP was piloted with pre-existing groups of mothers with intellectual impairment. New groups were established at each of the other four sites. A total of 42 mothers participated. Measures of psychosocial risk, including symptoms of depression, anxiety and stress were obtained one month prior and one month post intervention. In addition, goal

attainment scaling was used to assess socially valid outcomes. The standardised effect sizes were 0.40 for anxiety, 0.43 for stress and 0.54 for depression. These are substantially greater than the averaged effect sizes reported for parent training (Barlow, Coren & Stewart-Brown, 2007) and family support programs (Layzer, Goodson, Bernstein & Price, 2001). The social validity of the SLP intervention outcomes were evidenced by a high rate of goal attainment: the mothers were 'getting out and about' and utilising community resources, including places for leisure and for learning.

#### **STUDY AIM AND DESIGN**

The purpose of this study was to conduct a preliminary trial of the SLP in Alberta, Canada. The principal hypothesis was that participation in the SLP is associated with a marked improvement in the psychological well-being of mothers with intellectual impairment, including reduced stress, anxiety and depression symptoms. To evaluate the SLP, a multi-site, within-subjects, pretest post-test design was employed. To compensate for the inherent weaknesses of this pre-experimental design (i.e., with respect to ruling out plausible alternative explanations for any observed effect), and to obtain deeper insight into the SLP process and outcomes, the evaluation incorporated quantitative and qualitative data collection. Specifically, the evaluation incorporated psychometrically sound measures of psychosocial well-being (pre-SLP and post-SLP), goal attainment scaling, and semi-structured interviews with SLP facilitators and program participants. The supposition underpinning this approach to evaluation is that the convergence of evidence from multiple sources and methods (i.e., data triangulation) supports stronger conclusions.

Table 1. *Participant characteristics*

	SLP completed (n= 18) Mean (std) or %	SLP incomplete (n=15) Mean (std) or %
Age	31 (8.0)	30 (11.0)
Aboriginal	72.2%	46.6%
Married or common-law	44.4%	26.7%
History of special education	61.1%	53.3%
Did not complete high school	72.2%	86.7%
Disability income support (AISH)	61.1%	60.0%
Depression &/or anxiety disorder	66.7%	53.3%
Number of children ( <i>at home</i> )	1.4 (1.0)	0.9 (.64)

### *Recruitment & Participation*

Once ethics approval for the study was obtained (Pro00021086), information about the SLP and an invitation to take part in the pilot study was distributed to family support service agencies in Alberta. A total of six agencies responded to the invitation, including three rural and three urban-based agencies. Agency representatives were equipped with the SLP Facilitators Guide and resources, and took part in an SLP orientation session. One urban site struggled to recruit participants (e.g., through public advertisements and referrals) and subsequently withdrew. Two of the three rural agencies (including one mainstream family support agency and one agency providing specialized services for persons with Fetal Alcohol Spectrum Disorder (FASD) in the same region) joined together to deliver the SLP. Notably, the other rural agency also worked in collaboration with a special service for persons with FASD. Four sites therefore commenced the SLP, including two rural and two inner city sites. However, after successfully recruiting nine participants, one of the two urban sites had to abandon the SLP at the group-work phase (for reasons discussed below). A small budget allocation was made to each of the sites to offset the costs associated with implementing the SLP (e.g., staff ‘backfill, transportation of partici-

pants, group outings/activities and child care).

Most of the participants were recruited through agencies providing FASD services (i.e., PCAP: Parent Child Assistance Program). The participants cannot therefore be considered representative of mothers with intellectual impairment at large. Agency personnel identified mothers with intellectual impairment on their caseloads and through their networks. A total of 33 mothers with intellectual impairment gave their written informed consent to take part in the study and completed the pre-group phase of the SLP (i.e., goal setting and baseline measures). Of these, 18 mothers completed all three phases. Characteristics of the sample are presented in Table 1. Approximately two-thirds of the women who commenced the SLP were single mothers. Few had graduated high school, and most relied on disability income support (i.e., AISH: Assured Income for the Severely Handicapped). The majority of the mothers were aboriginal (i.e., North American Indian or Metis). Most had co-morbid depression or anxiety, and (like their own parents before them) a history of alcohol/drug addiction. Many of the participants had grown up in out-of-home care settings (e.g., in foster care) and now had one or more children of their own in state care.

### *Differences between mothers who did and did not complete the SLP*

Most of the mothers (13 of 15) who *did not* commence or complete the group phase of the SLP were recruited by the two urban/ inner city sites: Completion rates were high in the two rural locations. A number of factors contributed to this urban-rural divide. One factor was the high level of tumult in the lives of the urban participants. Before the group phase of the SLP could gain any traction some of the urban participants faced eviction (impending homelessness), broken relationships, bouts of substance abuse and/or child apprehension. Several moved out of town and were thus 'lost' to the SLP. Another factor was the high level of secondary support (i.e., in addition to the support provided by SLP facilitators) for participants in the two rural locations. The collaboration between generic family support service agencies and FASD service providers in the two rural locations ensured that each participant had an individual (PCAP) worker who encouraged and supported their participation in the SLP. By contrast, few of the urban participants had individual support workers: many were wait-listed for a worker at the time of the study.

### *Data collection*

In the pre-group phase of the SLP, participants completed measures of psychosocial well-being, and identified their individual, program-specific goals. In the post-group phase, participants completed the same measures of psychosocial well-being, and reported on their progress with respect to achieving their goals. In addition, in the post-group phase individual interviews were conducted with the facilitators and 15 of the 18 mothers who completed the SLP. Most of the interviews were conducted on-

site, in-person. A small number of interviews were conducted over the phone. The interviews were semi-structured, but conversational. Participants and facilitators were invited to share their experience of the SLP (positive and negative), including the SLP process and outcomes. Further, participants and facilitators were asked to reflect on how the SLP could be enhanced, and whether they would recommend the SLP to others (*and if so, how come?*). The interviews varied in duration from roughly 30 minutes to over 2 hours. With permission, all of the interviews were digitally recorded and later transcribed for analysis.

### *Measures of maternal psychosocial well-being*

- Depression, Anxiety and Stress Scales (DASS 21) (Lovibond & Lovibond, 1995): The DASS-21 is a well-validated 21 item self-report measure of negative emotional states: depression, anxiety and stress. Several studies with clinical and non-clinical samples have confirmed the factor structure of the DASS-21 and demonstrated acceptable test-retest reliability (Antony, Bieling, Cox, Enns & Swinson, 1998; Brown, Chorpita, Korotitsch & Barlow, 1997; Nieuwenhuijsen, de Boer, Verbeck, Blonk & van Dijk, 2003). Chronbach alpha coefficients of 0.91, 0.84, and 0.90 are reported for the depression, anxiety and stress scales respectively (Lovibond & Lovibond, 1995).
- The Tilden Interpersonal Relationships Inventory (IPRI) –Short Form (Tilden et al. 1990) was employed to obtain a measure of social relationships. This self report measure has 26 items yielding two subscale scores, one for perceived social support and the other for conflict in interpersonal relationships. This measure has

Table 2. *SLP Program Goals and Goal Achievement*

	% Setting this goal	Goal attainment	
		<i>Partially achieved</i>	<i>Fully achieved</i>
To meet people and make friends	89%	19%	69%
To feel more confident about participating in groups	89%	38%	62%
To learn more about places I can go to for information/help	89%	50%	38%
To learn more about places my whole family can go ... together	100%	44%	56%
To find out where I can go to do things I like doing	89%	31%	50%
To learn more about my strengths...	78%	14%	71%
To learn more about things I can do to help out in my community	89%	50%	31%
To feel more confident about going places in my community	89%	38%	50%
To learn some things that will help me get out and about...	89%	31%	50%
To get more enjoyment out of life	89%	38%	62%

demonstrated high internal consistency and good test-retest reliability (Kane & Day 1999; Tilden et al. 1994). Chronbach alpha coefficients of 0.91 and 0.81 are reported for the support and conflict subscales respectively.

- The Scales of Mastery and Constraints (Lachman & Weaver, 1998) was used to obtain a measure of perceived personal control, or ‘agency’. This 12-item self-report scale includes four items that tap one’s sense of mastery or effectiveness in achieving goals, and eight items that measure the extent to which one believes that there are obstacles or factors beyond one’s control that interfere with reaching one’s goals. Chronbach alpha coefficients of 0.70 and 0.86 are reported for the mastery and constraints scales respectively (Lachman & Weaver, 1998).

#### *Measure of goal attainment*

The SLP Program Goal Achievement Scale was developed to obtain a measure of psychological empowerment specifically related to SLP learning objectives and social relationships. This scale is comprised of ten items. The items, listed in Table 2, were derived from three sources. These were the nomological network of psychological empowerment developed by Zimmerman et al. (1988; 1992); findings reported by Booth and Booth (2003) and McGaw et al. (2002) from their evaluations of group-based programs for mothers with intellectual impairment; and, consideration of the SLP program focus. When administered in the pre-group phase of the SLP, mothers are asked to indicate the extent to which they want to achieve each goal on a three point scale, from ‘not at all’ through to ‘a lot’. Post-program, mothers evaluate their progress using a three-point scale, from ‘not close at all’ through to ‘I fully achieved this goal’.

## Data Analysis

The quantitative data were analysed using IBM SPSS v.22. A measure of each latent construct was obtained by calculating the mean value of the items comprising each scale. To determine whether measures of psychosocial well-being changed from Time 1 (pre-group phase) to Time 2 (post-group phase), paired-sample T tests were employed. Effect sizes were calculated using the formula given by Morris and DeShon (2002) for within-subjects studies. This approach takes the dependence among the means into account, and results in a standardized measure of effect size that is directly comparable to standardized measures of effect size obtained from between-subjects studies.

A generic approach was taken to analyzing the interview data, based loosely on the procedures outlined by Rubin and Rubin (2011). In the first stage of the analysis, each interview transcript was read and re-read. The task was to ‘grasp the particularity’ of each individual’s account: Prominent themes within each interview were highlighted. The second stage of the analysis involved coding all of the interview transcripts (i.e., systematically labeling concepts and themes as these appeared in the transcripts), and then identifying recurring themes across the interviews. The task was to reach an understanding of the SLP experience (i.e., to develop a composite picture) that was irreducible to the experience of any one participant or facilitator: Common themes were extracted.

## STUDY FINDINGS

### *It is worth the effort*

*“This has been something where not only have friendships been created but it has been something that the ladies have truly appreciated... and it is was an absolutely fantastic experience”*

Getting mothers into the program and then sustaining their participation was challenging for SLP facilitators. It was particularly challenging for facilitators at the two urban sites due to (a) a high level of chaos in the participants’ lives, and (b) a lack of secondary support (*described above*). Despite these challenges, and a sometimes disheartening attendance rate, the SLP facilitators persevered. The clear consensus among SLP facilitators was that “it is worth the work”. When asked to explain why this is, one facilitator declared “cause it’s amazing. It’s simple. To give somebody such a simple thing... It’s simple. It’s the connection. Just to let these moms support each other. It’s not clinical, and it’s not group therapy. It’s just... can you imagine for one minute what your life would be like without a friend?” This facilitator went on to explain that, “When you have (intellectual impairment and) FASD, inter-generational addiction... lots of times you don’t have a lot of family, family connections, supports. Bridges are broken. That’s why it was so cool to put these moms together and give them each other”. Tellingly, all of the facilitators indicated that they would like to implement the SLP again and would recommend the program to others.

<sup>2</sup> All names are pseudonyms



## Box 1. Implementing the SLP: What did not work so well?

### *What worked?*

The collaboration and complimentary expertise of generic family support service workers and FASD (i.e., PCAP) service workers. This was key to engaging and sustaining the participation of the mothers in the SLP.

Bringing experientially similar mothers together, and ‘trusting the group process’. Trusting the group process meant resisting the urge to “plan it plan it plan it” and to instruct (as opposed to facilitate). It meant “letting [the mothers] be themselves... letting them experience getting into a group and finding their way”.

The flexibility of the SLP, which enabled SLP facilitators and participants to ‘own the program’, innovating and adapting it according to their needs, strengths and interests, while at the same time staying true to the core principles and processes.

Using the community mural and other activities to provide concrete referents and context for discussion. Dialogue could not be directed or forced, but it could be facilitated, and often occurred spontaneously as the participants ‘did things’ together.

The stepping stones activity, which involved breaking strategies of action (e.g., how to ask for information, and deal with social situations) down into steps: “Because really it is just one step at a time [and when you break it down like this] they’re not seeing it as something huge.”

### *What did not work so well?*

The participants did not find the homework component of the SLP, which is contained in the participant workbook, very helpful. Moreover, the participant workbooks were frequently misplaced. One of the SLP sites adapted by completing the homework activities in-group, and storing the participant’s workbooks on-site.

Each week, SLP participants are asked to identify the barriers, for example, to utilising community resources (e.g., leisure and learning facilities), or becoming more involved in their community through volunteering. When the same barrier (i.e., the mothers’ fearful perception) was identified, week after week, the discussion and homework activities were perceived by some participants to be repetitious.

The SLP facilitators valued the flexibility of the SLP: “there is a lot of leeway to adapt it”. As one facilitator explained, “the programs I do here, they’re pretty canned. And you don’t have participants like that. You have to be flexible... [and with the SLP] you could go with the flow. Like if they wanted to talk more about things, for example, they talked about ‘well, I think people are judging me’. And we talked about why. What do you think is going on? And you’re not the only one that feels like that.” The flexibility of the SLP also enables facilitators to relinquish control. As one SLP facilitator noted, “a lot of times we think it will be easier [to implement a program] if we can just plan it plan it plan it, ...and we

think it will work because we planned it. I don’t think that is even close to how we should look at [the SLP]. I think the ladies really make it what it is.” Each group adapted the SLP according to their needs, and incorporated innovations while staying true to the basic underlying principles and processes. One group, for example, innovated by incorporating some role-play into the program, so that participants could see strategies (e.g., for handling difficult social situations) modeled, and then have the opportunity to practice and receive feedback. Another group incorporated activities into the group program, such as preparing a healthy lunch together.



Figure 1. Thematic findings

*I feel scared all the time*

SLP facilitators faced a variety of challenges in implementing the SLP. By all accounts, the single greatest challenge was “just getting the mothers into the program”. The SLP sites provided transportation and on-site child care to eliminate some foreseeable barriers to participation. One SLP site, for example, arranged for a community bus to pick the participants up each week at their door and transport them home afterward. However, the main barrier to the mothers’ participation in the SLP was psychological. It was the same barrier that kept many of the mothers from getting out of the house and, as one mother put it, “being a part of society”. This barrier was **the perceived threat of negative social evaluation**. The mothers were painfully aware of their so-

cial isolation and they wanted to connect with others and make friends. However, the mothers were also fearful. They did not expect to be understood and accepted by other group members; to feel like they belonged. Rather, they feared that their perceived inadequacies would be exposed, and they would be judged and marginalised. One participant, Rebecca<sup>2</sup>, explained “that is what kind of overtakes all of us girls, because we’re afraid of being judged”.

For the SLP facilitators employed by generic family support service agencies, the challenge of enticing isolated and fearful mothers into attending their programs—*when this is not mandated by the child and youth protection authority*—is a familiar one (i.e., it was not unique to the SLP). One facilitator explained, “oftentimes we find that our more at-

risk parents will feel threatened by other mothers, or feel judged...”. Another observed that “we are missing that target audience. These moms should be here [utilizing our services]... those are the moms who need to be here. But they’re just feeling like they can’t come. They’re too afraid... like, ‘they won’t understand me. I won’t understand them. I don’t get what they are saying. They’re judging me’...”. A third facilitator noted that, “the moms that do come [to our programs] tend to be white, middle income. I do find that the mom’s groups, they’re a little bit hard. I want to say cliquy. It makes it hard for moms like these moms to come in...” For these family support service workers, delivering the SLP in collaboration with PCAP workers represented an opportunity to build bridges, that is “to bring some people into the centre who normally would not come”. One facilitator noted, “we’re hoping that those ladies [will get to] know our staff, see a friendly face, and be able to come in... and I’ve seen them. We have a used clothing store up front, and even today there was one of the ladies that come in”.

### *I just don't feel like I belong*

Many factors contributed to the fearful perception and social isolation experienced by the mothers who took part in the SLP. Some mothers simply did not feel like they were acceptable to others (i.e., like they belonged), on account of their disability. The expectation of being rejected could be learned early in life. For instance, one mother, Theresa, recalled “my mother gave me up because I am FASD. She had me and she drank. She didn’t accept me, that’s why she gave me up”. Theresa grew up in a series of foster homes and moved back to her home town as an adult. However, Theresa reported, “I have not been accepted here... because I was raised elsewhere... they won’t look me in the eye... the people

here... My own people”. Other mothers had experienced ‘inclusion’: they had found acceptance in a group that liked ‘to party’. However, for the sake of their children, and to be seen to be a ‘good mother’ (i.e., one that is ‘clean’), they had cut ties. As Mandy explained, “I used to be addicted to meth. I’ve been clean for two years. Ever since I kind of just cut my circle off”.

The mothers who took part in the SLP generally felt embarrassed by their disability. To be in the community was risky because their disability might be exposed: *It is difficult to ‘pass’ as normal, that is, as someone who belongs*. Ordinary activities, such as withdrawing cash at an ATM, could be risky. Mandy, for example, explained, “So I have a problem sometimes at the bank and there’s a big line there. And I don’t like holding people back. And so I have problems sometimes getting all the money out. So I’m like “ok, ok”. And then I’ll just get flustered and all the people look at me and stare at me. And then I’ll just get frustrated and just leave. And then I’m like “that was so embarrassing”. That is the scariest thing ever... And I try to hurry and I hear someone say “um, hurry up”. Then I’ll just be like... ‘Okay, that’s it. Goodbye’. And I’ll leave quickly”.

Some of the mothers were hesitant to reach out to others, including family members, because they did not want to feel like, or they had been made to feel like, they were a burden. Patricia, for instance, shared, “... like whenever I needed somebody around to talk to, my sisters tell me “oh, I’m too busy”, or “I can’t”. Like when we go visit and he starts crying they ..., I don’t know, it’s probably just me... but I feel like they are annoyed. So I always leave. And they’re like “oh how come you left?” and I just tell them ‘because you were getting annoyed at my son’. I can’t be around people like that. Like when I feel like

I'm a burden to someone I just don't bother with them ... It's just hard". The toxic combination of perceived social isolation and burdensomeness places mothers like Patricia in a high risk category for suicide (Van Orden, Witte, Cukrowicz, Braithwaite, Selbey & Joiner, 2010). Notably, for Patricia and other mothers who took part in the SLP, it was their children who gave them reason to live. In this context, the threat of 'the welfare' coming to take their children away could be experienced as if it were a threat to life itself.

*I am not alone in this: These moms were just like me*

*"At first I was sort of nervous and then I got to know some people... who they are and what they're about and stuff... and I didn't feel so... stupid"*

From the perspective of the mothers who took part in the SLP, the most significant outcome was the insight that they were not alone. That is, they discovered that other mothers struggled too, and felt much the same way they did: flawed and fearful. One of the participants, Michelle, discovered that "they (the other girls) have the same scared things and stuff. They're scared to go in [to town] and like do things, and we were all scared to come here...". Another participant, Allana, learned that "I'm not the only one that is dealing with this, or feeling like this... It was like, 'wow, huh, so I'm not so bad'... that was the eye opener ... it was like I'm not alone in this". Similarly, Brenda explained that "I liked it because there were other girls in the group that were going through the same situations as me. That's what I liked about it. ... I thought I was the only one who stayed at home in the four walls". The SLP facilitators also highlighted this outcome. One facilitator observed, "[what the mothers took away from the

SLP was the realisation that] 'I'm not struggling here alone. Everybody struggles.' It's the struggle without any support. That's the killer". Reflecting on the outcomes of the SLP, another facilitator suggested that the mothers learned that "they are not alone. There are other people out there struggling with the same things that they struggle with, and have the same fears and insecurities about taking your kids [out into the community]... and sort of feeling that you're not a good parent. Like you're an outsider".

The opportunity to be in a group with experientially similar others set the SLP apart from other group-based programs the mothers had attended. Theresa said "it was good to talk with a bunch of people who are just like me. Not like other groups where you have a bunch of other people who don't know anything [about what your life is like]... they don't really know what you are saying. But with this SLP, it was good because we know what's going on... It's just us. Our group. I like that." Another participant, Shaunie, made a similar point, "we were all in that kind of situation... fighting for our kids. We all have some anxieties and problems in this group. Whereas when you're in the parenting program you seem like you are the only one going through that and it made you a target". Likewise, Jasmyne observed, "so [the SLP] was very interesting because usually when you go to those kinds of groups as mothers you meet a lot of women who are well off. And it (the SLP) was more for people who were scraping by as like myself".

*"I think this program would be good for other moms. Especially the ones like myself, feeling alone. It (the SLP) would give them a sense of belonging and confidence. So they can think 'I am not the only one going through this problem, other people are too'."*

## *We were helping each other*

*“The part I liked most about it was how we met other moms. And seeing their situations, and how they coped, and how they do that. That’s the part I liked the best”*

For the SLP participants, being in a group with experientially similar others had many benefits. ‘Feeling safe’ was one. Andrea said that “it was nice that we could come to this and feel safe”. In a group with experientially similar others, the mothers were not quite as fearful of being judged as they might otherwise have been. Carol said “I liked the non-judgemental side to it. Considering I’m a recovering addict... that was one of the main things that was kind of a deterrent (to joining a group)... always feeling like your being judged and stuff. I was never judged there... And it was open, which is good then everyone has their own little tidbits to put into that”. One of the SLP facilitators also commented, “(what stood out for me was) just how accepting they are of each other. They just accept each other. They have so much in common. That is what is so simple about this. You’re all moms. And they get that”. Notably, some mothers, when they missed a week of the program, were hesitant to return to the group for fear of reproach. ‘Feeling understood’ was another benefit. Jessica insightfully observed that “It’s easy to get people to help you, but it’s harder for them to see where you are coming from”. In the SLP, the mothers felt like other group members understood where they were coming from because they had faced similar challenges themselves. Rhaina said, “(a)ll these girls understand”.

A third major benefit associated with being in a group with experientially similar others is ‘reciprocity (mutual support)’. Perhaps because the

mothers who took part in the SLP felt safe and understood, they were open to learning from other group members, and they discovered that they also had knowledge to share. As Mandy explained, “It was easier to understand what we’re all going through and at the same time it’s easier because of the people that needed information I was able to provide. And if there was anything I needed they were able to provide it... we were helping each other, which was really nice”. Theresa, among others, concurred, “I thought I was the only mom going through this, and then I found there was other moms. So when we were in the group we talked to each other and we share our experiences. We share what we’re going through and I learned from them. That is why I liked this group. You’re sitting there and if I asked a question, if I need something that I don’t know, one of the girls in the group will know. And then I’ll be able to hear from them and know what’s going on”.

The mothers who participated in the SLP shared many of the same everyday concerns. Rhaina voiced the thoughts of many when she shared, “I worry about food, baby things, rent. That’s what I worry about”. Esther said, “I worry about a lot of things. ... I worry about my son, when I get my son, and things like that... I worry about if my house is clean, and when he is going to come back, and if I have food for him.” Through the SLP the mothers were able to share information with each other about community resources that could help them deal with their everyday worries. Rhaina, for example, reported that “I found out about (*name of agency*) through the SLP, [and they were able to help me with things like] blankets, diapers, clothing, and subsidies [for a bus pass].” It is perhaps because the mothers were experientially similar (e.g., ‘just scraping by’) that

they had information to share that was useful to, and valued by the other group members.

Some of the SLP facilitators were perhaps a little surprised by the extent to which the mothers helped one another. One facilitator commented, “the group concept I could never have imagined to have worked out so wonderfully with these women... It was absolutely amazing the dynamic that happened when they got together, ... just seeing them together and how that empowered them. That filled their buckets. Seeing each other.” Another facilitator gave this illustrative example, “There is a mom, Gloria, she’s recovering, she was using drugs. When she came she was all fidgety. I was like ‘what’s wrong?’ And there was a certain place where she needed to sit. And even just for her to get here each week, that was like, Yay! So she kind of helped us to understand the things that she goes through... she has a lot of anxiety. So we kind of focused on what she could do... some strategies... It was kind of neat because they each helped each other. That was kind of exciting.” A third facilitator observed that “they came up with amazing solutions, like ‘take a notepad’, ‘write down what they’re saying’, ‘check it out online’, ‘bring a friend’.”

It is important to note that the level of group cohesion did vary across the SLP sites. The SLP facilitators at both rural sites reported a very high level of group cohesion. At these two sites “the ladies really made it what it was”. It took longer for the mothers ‘in the city’ to come together as a group. The interview data suggest that it was one facilitator in particular, rather than the mothers themselves, who really ‘made’ this group. One of the urban SLP facilitators observed that, “the personalities at first didn’t go very well together... but as they spent time together they began looking forward to it, and wanting to

come... then it was like, ‘whatever, I’ll tolerate you so that I can feel accepted’. And accepted is what they felt I think, with each other, and not judged right...”.

*I learned how to get out more*

*“I have gone out into the community and done a lot of things that I didn’t do before”*

Entering the program, almost all of the SLP participants (16 of 18) wanted to learn some things that would enable them to ‘get out and about’ in their community. Mandy said “I want to get out and about... gets me feeling good about myself”. Over 80% of the mothers reported either fully or partially achieving this goal. Rachelle, for instance, said that “It taught me how to get out more... because at home, I think, ‘oh I can’t go because I’ll meet these people (aunties, uncles, elders) there,... and they will ask me for money or something [and you can’t say no to your elders]’, but the group taught me how to avoid it... And I did that pretty good. I know what to do now.” Similarly, Esther thought the SLP would be helpful to other mothers because “It will teach them how to not always have boundaries where you’re just staying in your house. You’ll be able to go places. You learn it’s just one step at a time... [and then it doesn’t seem so huge]. Now I go out more. Before I really wouldn’t go out. I wouldn’t do anything. Now, I go out more. Because this program is helping me get out more. I go to the library. I go out more. Before I would just stay at home. Just be inside my house and go nowhere. And this group helped me get out more.”

We asked SLP facilitators to describe a moment in the program that ‘stood out’ for them. One of the facilitators shared this story: “(Anna) told me that she (was reluctant to) walk up to the front desk

and ask about play programs... she said, 'they're going to start talking and I'm not going to remember'. That stood out to me because we talked about what are some other ways that you can... I know I made her laugh. I said, well, we pointed out the fact that you could get the receptionist to write down what she said. And she will most likely make it a lot shorter if she has to write it down! Or you phone and ask them to repeat it. Or you look online. And I know Anna did a few things on her own after that". Indeed, most of the mothers were able to give concrete examples of how they were now doing things on their own, being in the community, and pursuing their goals. Shauna, for example, who like many other SLP participants had the goal of continuing her education, reported that "I already went to the college and got a book... courses I want to take... I was really scared at first. (I told myself) 'Just go inside and get the book'. After I did it I was like 'that wasn't that bad, I can do it'". Another mother, Jenny, had the goal of getting out and doing more with her son, and with great satisfaction she declared that "I actually managed to go swimming three times with my son!"

#### *I found out things about myself too*

*"I feel really lost. Like I don't know who I am. All I know is that I'm someone's parent. I'm someone's girlfriend. I don't know who I am any more. I'm kind of having a struggle finding myself again... I just wish it (the SLP) was still going because I was sort of finding ways to slowly get back into who I am and who I'm becoming."*

Most of the mothers (14 of 18) wanted to learn more about their strengths, and 85% reported either fully achieving or partially achieving this goal. One of the SLP facilitators observed "when they did that part about your strengths and skills... They

were... for some of them it took a little bit. I don't know if they ever sat down and appreciated the things in themselves, like being patient, loyal, funny..." One of the participants, Joyce, said "I found out things about myself too... Like I found out that I'm like determined. I plan ahead a lot. I'm a good listener. I know I'm an awesome mom. Staying on the wagon, that's a good one. Learning to be healthy. I'm very giving, I can't help that one. I'm helping people out a lot. See I've learned a lot of things about myself. I didn't know I had all those qualities." Participating in the SLP also had some impact on how the mothers' perceived others. Specifically, they became less (defensively) critical. *Notably, people who experience prolonged social isolation are often 'primed' to find fault in others. This is a natural defense mechanism when we expect others to find fault in us (Cacioppo & Cacioppo, 2014).* Shauna, for example, observed, "I had this idea set in my head... I was a little embarrassed about my FASD and I didn't want to be around people that were, sort of, less... in that way. So I guess I was judgemental at first. And then I realised that, you know what, we all have our problems with our FASD. But it doesn't mean we don't all have our gifts too... You know, and that's what I was learning. Some people have gifts that I was like 'wow, you could do that? Holy crap! That's stuff I can't do'".

#### *I don't feel confident, but I feel I am slowly getting there*

*"I know how it feels to be isolated. I used to not want to be around other people... never was open... I kept to myself, and now I am not like that".*

Entering the program, most of the mothers (16 of 18) wanted to feel more confident about going places in their community and participating in

groups. Angela spoke for many when she said “I’m tired of being cautious, of feeling unsafe”. At least one half of the participants reported fully achieving these goals. Others reported partially achieving these goals. Ashley said, “I don’t feel confident, but I feel like I’m slowly getting there”. Another mother, Angela, observed “I feel a bit more confident about going places, because before it was like the big issue... because I am so self-conscious”. Similarly, Jacquie said, “(t)he main thing I got was it’s okay to be going into something new. You know you’re scared, but it’s okay, and you just got to take the leap to overcome that fear.” The growth in confidence reported by these and other SLP participants was not, however, associated with any observed change on the Scales of Mastery and Constraints (see Table 3), a measure of perceived personal control.

*“You know I’ve been getting out a lot more... well, forcing myself to get out because it is not good to stay in. It’s about being brave to go on the bus by myself...”*

Some of the mothers reported increased confidence in dealing with difficult social situations, and in this context, regulating their emotions. One of the participants reported, “my anger has been better since I’ve been going to it”. Another mother, Helen,

gave an illustrative example of how she was learning to inhibit her defensive impulses: “I was so scared to take my baby places because she might scream. And I took her to the bank one day. And she’s screaming. And this one lady, a really grouchy old lady just yelled at my baby. And that made her cry. And I was like, ‘I have to maintain... not yell back. Not get mad. I’m just like ‘that was rude’. And she’s like ‘well tell her to be quiet’. I was like, ‘we’re just going to walk away... I don’t want to yell... I’m not going to get mad’”.

The SLP facilitators noted the mothers’ growth in confidence. One facilitator reflected, “I think they took away that they are probably stronger than they think... and that they can come to places like this (the family support centre)... like we are not all wearing lab coats and marking down every move that they make”. The facilitators also shared several stories of transformation. The story of Eliza is one: “Eliza, she’s so shy. Even one-on-one, she’s so shy... [So it was our second to last week, and only three of the moms showed up.] It was the week they did their community outing on their own. They actually separated from their kids and left them in our facility [which was a really big thing for them]. We made a list of their questions [beforehand]... what they were going to learn at the library... and when they came

Table 3. *Psychosocial well-being*

	Pre-SLP mean (sd)	Post-SLP Mean (sd)	Standardised effect size (Cohen’s d#)
<b>DASS Depression</b>	<b>1.40 (.89)</b>	<b>1.01 (.66)</b>	<b>0.57</b>
<b>DASS Anxiety</b>	<b>1.14 (.56)</b>	<b>0.78 (.45)</b>	<b>0.71</b>
<b>DASS Stress</b>	<b>1.86 (.82)</b>	<b>1.41 (.49)</b>	<b>0.60</b>
SMC Mastery	3.25 (.51)	3.24 (.45)	<i>no change</i>
SMC Constraints	2.31 (.61)	2.53 (.60)	<i>no change</i>
IPRI Support	3.90 (.67)	3.89 (.60)	<i>no change</i>
IPRI Conflict	3.73 (.83)	3.38 (.69)	<i>no change</i>

# adjusted for the dependence among the means (Morris & DeShon, 2002)



back it was blah, blah, blah [they couldn't stop talking about it]. Next group I said, "Eliza, lots of these people weren't at your outing last week. Tell them what you learned." She stood up. Everyone else was sitting. So basically she was public speaking. And she gave this amazing spiel." Eliza recognised this change in herself, as she recalled "[when I went to group for the first time] I was like 'everyone's all talking', and I'm sitting by myself. I didn't talk. And then at the end of class, I'm like yapping away. I liked it. I was not shy and I was always excited to come. I'm like 'woo. I get to go drop my baby off and hang out with the girls'".

*I made new friends*

*"They really enjoyed being together. They really enjoyed that networking. It was just amazing" (SLP Facilitator)*

No change was observed, from the first to the third phase of the SLP, in the mothers' scores on the Interpersonal Relationships Inventory, which is a measure of perceived social support. Notwithstanding, most of the mothers reported receiving social support, including informational and emotional support (as outlined above). Moreover, before the group phase of the SLP commenced, most of the mothers (16 of 18) wanted to make new friends, and in the post-group phase 88% reported either fully achieving or partially achieving this goal. Esther said, "I like how most of the girls before we came here we all wanted friends out of it. And that's what we got". Shauna said "I didn't think we'd have anything in common, I wouldn't like them... now I am friends with all of them". Another mother, Joyce, also talked about the friends she made. Joyce recalled, "before I came here I had no friends. Now I'm letting people in more... I was able to get out more and see people

more, and make more friends than just being by myself... That's why I like this program... Because all those girls, we don't know each other and we were just sitting there... Then we start talking and start opening up more and more. And all of a sudden all of us are talking before we even go into the room. I made a lot of new friends. I'm on facebook with them. I like that too because I can talk to other women about things and they'll know things that I don't know and then they'll ask me a question to see if I know it and I like that because then you can just sit there and talk really good".

*It got me out of the house, and 'out of my head'*

*"It helped me get out and socialise, so I'm not stuck in the house with the kids all the time and feeling isolated"*

By their own accounts, the mothers who took part in the SLP spent too much time "in the four walls", alone with their thoughts, which were often negative and self-defeating. The SLP gave these mothers "something to do and look forward to": an opportunity to get out of the house and 'out of their heads'. As Rebecca reported, "it was good to get out of the house instead of sitting there all the time, stewing [in negativity]..." Similarly, Shauna observed that, "ever since I got pregnant I just pushed everyone away and just kept to myself.... I just felt like I was a burden to everyone around me and that's why I kept to myself... And then when I came here, it was a bit of a relief, just to be with other mothers..." Another mother, Angela, explained "(t)hat's why I kept coming. It got me out of the house ... and oh, I needed to get out of the house! And that (the SLP) helped me do that, so I felt like I was part of society, and that was really important to me". In addition, most of the mothers described the group phase of the SLP

as “fun”, or as one mother put it, “full of good energy”. Aleisha, for example, said “we goofed around. It was fun. We had a blast. Everybody had everybody laughing”. One of the SLP facilitators reported, “they looked forward to getting together [because] they don’t get out very often. They’re isolated in so many ways. So this has been huge for a good number of them”. The uplift of such positive social interaction—of fun and laughter—may explain, at least in part, the positive change in psychological well-being observed in the SLP participants (see Table 3).

*“when we got into doing the mural and stuff like that, we got to discuss it and talk and then apply it... that was fun”*

*I am looking forward to the future*

Significant differences were found between pre-SLP and post-SLP measures of the participants’ psychological well-being. Following the group-phase of the SLP the mothers reported meaningfully lower levels of depression, anxiety and stress. The standardised effect sizes ranged from 0.57 for depression to 0.71 for anxiety. These are large by comparison with effect sizes typically reported for parenting/family support programs in the literature (Barlow, Coren & Stewart-Brown, 2007; Layzer, Goodson, Bernstein & Price, 2001), and larger than those found in the Australian pilot of the SLP (McConnell, Dalziel, Llewellyn, Laidlaw & Hindmarsh, 2008). However, due to the lack of any comparison group, it is uncertain whether the observed change is attributable to the SLP or to some other phenomenon such as *regression toward the mean*. Notwithstanding, the data from goal attainment scaling and interviews generally support the conclusion that participating in the SLP had a positive effect on the mothers’ psychological well-being. For example, before the group

phase of the SLP, most of the mothers indicated that they wanted to get more enjoyment out of life, and 100% reported either fully achieving or partially achieving this goal. In addition, a number of the mothers described a transformation in their outlook, *from gloomy to more hope-full*. One mother, Tracy, shared, “I get discouraged really easy. When I get discouraged I just stay home and do nothing. I suffer depression. I tried to commit suicide twice. But right now I’m just looking forward to the future, finding who I am... To better my life” And another mother, Sherri, concluded that “the program helped me to learn to be more positive in myself ... to be more happy”.

## DISCUSSION

The mothers with intellectual impairment who took part in this study were surprised to discover that there were others mothers ‘like them’: mothers who viewed themselves as congenital outsiders, and who were fearful of being exposed, judged and rejected. The discovery that they were not in fact alone, *as well as the weekly positive social interaction between group members*, may account for the observed reduction in depression, anxiety and stress symptoms between the first and final phases of the SLP. This measured ‘effect’ could be caused by other factors: the inherent weakness of the within-subjects, pretest posttest design means that we cannot rule out plausible alternative explanations such as regression toward the mean. However, the goal attainment and interview data strongly support the conclusion that the SLP had a positive impact on the self-understanding, social connectedness and psychological well-being of the mothers who completed the program.

The findings of this study are generally consistent with those observed in the Australian pilot of the SLP. The observed effects of the SLP on measures of psychological well-being (or more accurately, ill-being) were larger in this study. However, no meaningful change was observed on measures of perceived social support or perceived personal control. Notwithstanding, the goal achievement and interview data suggest that the mothers who completed the SLP achieved a greater awareness of barriers, “learned some things” that enabled them to be in the community, and made new friends. The evidence also suggests that many of the participants now have a greater degree of confidence with respect to participating in group programs and accessing community resources, although several mothers noted that their confidence was “not quite there yet”. We expected that the measures of perceived personal control and social support that were used in this study would be sensitive to such changes. The results of this study (*and to a lesser degree, the results of the Australian pilot of the SLP*), suggest that this may not be the case.

The difficulty inherent in the task of, firstly engaging the willingness of socially isolated mothers with intellectual impairment +/- addiction to ‘give the SLP a try’, and then sustaining their participation (through the adverse events and circumstances of their lives), cannot be understated. One site that was initially interested in implementing the SLP could not recruit any participants. Another site recruited nine participants, and despite their ‘over and above expectation’ efforts to make it work, had to abandon the SLP in the group phase. At each of the other sites, the SLP facilitators had to be creative and invest considerable effort to keep the program running. One of the lessons that might be learned from

this pilot of the SLP in Alberta is that the program may only be practicable when the participating mothers have more stable living arrangements and are at least partway down the path of recovery (i.e., have been ‘clean’ for at least some time). Another lesson is that the SLP is mostly likely to work when the participating mothers have the support of an individual worker (and transportation and child care is provided). Without such individual support, the events and circumstances of these mothers’ lives may simply overtake them, resulting in low or inconsistent attendance, or withdrawal from the program.

Recent research in the field of loneliness sheds some light on why the SLP, *or for that matter, any group-based program for socially isolated people*, can be difficult ‘to get off the ground’. The evidence suggests that feeling socially disconnected is tantamount to feeling unsafe, and this makes one hyper vigilant for social threats (i.e., the threat of negative social evaluation) (Baumeister & Leary, 1995; Cacioppo, et al., 2011). Loneliness researchers, Hawkley and Cacioppo (2010), explain that unconscious surveillance for social threat produces cognitive biases: people who experience prolonged social disconnection tend to perceive the world as a more threatening place and expect more negative social interactions. They are also more likely to attribute their social disconnection to factors outside of their control. Perceiving (unconsciously) that their safety is threatened (by factors outside of their control), lonely people may actively distance themselves from others (i.e., the ‘flight’ response), and/or enter social interactions *primed*, neurobiologically and psychologically, to find fault in ‘the other’ and to respond to any perceived social threat with hostility (i.e., the ‘fight’ response). In light of this research, it is important to understand that, when socially isolated

mothers with intellectual impairment receive an invitation to take part in a group program, such as the SLP, their deep unconscious (limbic brain) may scream “no, it’s not safe”.

Despite the significant challenges and effort involved in engaging mothers in the program and maintaining their participation, the SLP facilitators were, without exception, quite clearly rewarded by the experience. “It was worth the effort”. Generic family support service workers were interested in findings ways to reach mothers “who do not usually come in”. *Notably, a previous study found that mothers with intellectual impairment are among the least likely to access generic family support services in Alberta, and those that do tend to report lower levels of satisfaction (McConnell, Breitzkreuz & Savage, 2012)*. FASD (PCAP) workers, for their part, were interested in finding ways to ‘plug their clients into’ the community. As one FASD service worker put it, “they were wondering how to connect with our clients, and we were trying to figure out how to get our clients to their program”. In two different rural locations, the SLP served these interests well. Agencies and individuals, who by their own report were “accustomed to working in silos”, came together to offer the SLP, and enjoyed some success. The SLP was described, by different workers, as “eye-opening”, “amazing”, “a fantastic experience” and a “tremendous success”. Perhaps the most telling piece of evidence is that each SLP facilitator indicated that they would like to implement the SLP again and would, without reservation, recommend it to others.

An open question is whether participation in the SLP will have any lasting benefit for the mothers involved, and their children. The SLP was only ever imagined to be ‘a rung on the ladder’ leading to greater social connectedness and community partici-

pation. In theory, having taken a first step, the second and third steps will be easier. In a ‘growth spiral’ we might hypothesise that, with increased awareness and confidence, the mothers’ may be more inclined to step out of “the four walls”, and in doing so, their awareness and confidence will continue to grow leading to greater social engagement, and so on. This hypothesis may seem reasonable enough, *IF the assumption is made that the mothers’ fearful expectations (i.e., of negative social evaluation) are not entirely rationale, and the community is ultimately welcoming and inclusive*. Yet, mothers with intellectual impairment are all too often judged, ostracised and worse (e.g., physically, sexually and psychologically assaulted). Their fear, for example, of ‘the welfare’ coming to take their children away, *and for reasons that genuinely are beyond their control*, is well justified (Booth, Booth & McConnell, 2004; McConnell et al., 2010; McConnell, Llewellyn & Ferronato, 2006). The question then is what happens when the mothers’ step out and their fearful expectations are confirmed? Clearly, a longer term project is needed to gather follow-up data in order to determine whether participation in the SLP has any benefits over the medium to long term, and whether the observed benefits translate into more positive outcomes for their children.

### *Conclusion*

Many of the mothers who took part in the SLP were “sad” that they no longer had ‘group’ to look forward to each week. Some of the mothers were committed to staying in touch, for example, through Facebook. However, others fearfully anticipated being disconnected and *alone* once more. Based on (1) the mothers’ positive experience of the group phase of the SLP, the demonstrated potential of the SLP to promote transformatory change in the

mothers' outlook, and the wish of many for the group to continue, *and*(2) the harsh reality that these mothers will continue to encounter social threat (i.e., the threat of social exclusion), our recommendations are:

- **Family support (Parent Link Centre) workers and PCAP workers across the province of Alberta consider 'teaming up' to offer the SLP as an adjunct to other services; and,**
- **Agencies/workers who offer the SLP consider how opportunity could be created<sup>3</sup> for the group-phase to evolve into a continuing Self-Advocacy group.**

The formation of a Self Advocacy group would be a natural extension of the SLP: Self-Advocacy groups have the same basic underlying principles and processes. The benefits of membership of a Self Advocacy group include but are not limited to the opportunity to speak-out and feel listened to; experience a positive social environment; form and maintain friendships; support and learn from other group members; develop a more positive self-concept; and, act collectively to confront disabling social barriers (e.g., by calling attention to professional-centered as opposed to client-centered practices) (Beart, Hardy & Buchan, 2004; Goodley, Armstrong, Sutherland & Laurie, 2003).

The social connectedness afforded by ongoing (SLP/ Self Advocacy) group membership may be especially important to mothers with intellectual impairment + addiction who, by definition, have more

limited cognitive resources. Prolonged social isolation depletes self-regulatory resources, which are needed to inhibit impulsive and pre-potent (habitual) behaviours, and strategically control attention and plan-fully pursue longer term goals (Ayduk, Mendoza-Denton, Mischel, Downey, Peake & Rodriguez 2000; Baumeister, Brewer, Tice & Twenge, 2007; Stillman & Baumeister, 2013). When the self-regulatory resources of mothers with intellectual impairment + addiction are depleted, they may struggle, firstly to 'stay on the wagon', and secondly, to inhibit pre-potent parenting responses so that new parenting skills can be implemented. In other words, ongoing (SLP / Self Advocacy) group membership (or rather, the social connectedness this affords) may enhance the outcomes of drug/alcohol counseling and parenting training programs. Indeed, it is questionable whether such traditional interventions can be effective for these mothers *over the long term* if the mothers remain socially *disconnected*. This is an important question for future research.

<sup>3</sup> Agencies/workers can create/present opportunity but they cannot unilaterally establish a Self Advocacy group. By definition, self advocacy groups are created and driven by group members.

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