

Change and Recovery: Culturally Appropriate Early Childhood Programmes with Refugee Families and Communities

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The STARTTS Early Childhood Programme at the NSW Service for the Treatment and Rehabilitation of Torture and Trauma Survivors (STARTTS) has been developed in response to the complex refugee experiences of very young children, their families and communities. This biopsychosocial and systemic model is informed by neuroscience, attachment theory and current knowledge of the nature and impact of refugee-specific trauma on very young children and their families. It addresses the complex interactions between, social, cultural and political factors within the trauma and recovery environments, as they influence the clients' presentations and the choice of interventions with families in cultural transition (FICT).

This paper provides a background to the STARTTS programme, and reports on the results of a Community Based Participatory Research (CBPR) project with the Karen and Mandaean refugee communities. It explores perceptions and cultural views of signs and symptoms related to early childhood trauma. It also explores help seeking preferences in relation to the recovery, settlement and health needs of families with young children. This research has led to ongoing collaborative and consultative processes with those communities, resulting in the development of services and referral systems, which will build a comprehensive and culturally appropriate early childhood programme.

■ **Keywords:** Early childhood, refugees, trauma, biopsychosocial, systemic, collaboration

Effect of Early Childhood Trauma on Brain Development

The STARTTS programme is informed by evidence about brain development (Centre on the Developing Child at Harvard University (CDCHU), 2007, 2010, 2011; Cozolino, 2006; Ludy-Dobson & Perry, 2010; National Scientific Council on the Developing Child (NSCDC), 2005, 2007a), the impact of trauma on brain structure in the first 5 years (CDCHU, 2011; Cozolino, 2006; NSCDC, 2004, 2005, 2007b; Schore, 2001) and the crucial role of attachment and affect in the child's development (Brisch, 2012; Reebye, Ross, Jamieson, & Clark 2013; Schore, 2003a & b). These studies have been described in more detail elsewhere in relation to the STARTTS programme (Signorelli & Coello, 2011).

Trauma is often expressed in the very young child through implicit, somatic, behavioural and emotional signs, which need to be considered in assessment and intervention. These include:

- physical symptoms or illnesses (CDCHU, 2007; Greenspan, 2011; Perry, 2006; Tunnecliffe, 1996; Van der Kolk, 2005, 2010; Van der Kolk & Saporta, 1991);
- delay or regression in developmental milestones (CDCHU, 2007, 2010, 2011; NSCDC, 2004, 2005, 2007a, 2007b, 2008, 2010; Tunnecliffe, 1996);
- emotional and behavioural dysregulation, and social difficulties (Tunnecliffe, 1996; Van der Kolk, 2005, 2010);
- learning and cognitive deficits (CDCHU, 2011) and
- implicit and explicit memory of traumatic events (Azarian, Lipsitt, Miller, & Skriptchenko-Gregorian, 1999; Signorelli, 2014).

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Early intervention is crucial to reverse these adverse changes in brain function (CDCHU, 2007; NSCDC, 2005, 2007a, 2007b), prevent or repair the disruption to attachment (Schore, 2001), prevent life-long mental health symptoms (CDCHU, 2007, 2010; Ludy-Dobson & Perry, 2010; NSCDC, 2005, 2007a, 2007b; Perry, Pollard, Blakley, Baker, & Vigilante, 1995; Schore, 2001; Van der Kolk, 2005, 2010) and help the child to “catch up” in their development (CDCHU, 2011; NSCDC, 2005, 2007).

Influential Theories and Intervention Models

Several Western intervention models address these trauma recovery and developmental goals (Blaustein & Kinniburgh, 2010; CDCHU, 2007, 2010; Cohen & Mannarino, 2010; Cozolino, 2006; Greenspan, 2011; Herman, 1997; Interdisciplinary Council on Developmental & Learning Disorders (ICDL), 2000; Perry, 2006; Van der Kolk, 2005, 2010). Attachment studies of Schore (2001, 2003a, 2003b), Tronick (2007), Brisch (2012) and Powell, Cooper, Hoffman and Marvin (2014) inform the dyadic basis of the STARTTerS programme.

The STARTTerS programme uses such modalities as music therapy (Creighton, 2011; de L'Etoile, 2011; Edwards, 2011; Signorelli, 2011a, 2011b), sensori-motor activities (De Gangi, 2000; Ogden, Minton, & Pain, 2006; Warner, Cook, Westcott, & Koomar, 2011), dramatic play (Coello, 2014; Eines & Mantovani, 1980) and play therapy (Cooper, 2009), together with psychoeducation and counselling for the care giver (Signorelli, 2012). Other influences include *whole-brain/brain-based approaches* (Arden & Linford, 2009; Siegel & Bryson, 2011), *polyvagal theory* and the *social nervous system* (Brisch, 2012; Cozolino, 2006; Porges, 2011; Schore, 2001, 2003a, 2003b) and the *window of tolerance* (Ogden et al., 2006; Siegel, 2009). Some case vignettes and STARTTerS interventions have been described elsewhere (Signorelli, 2011a, 2011b, 2012, 2013a; Signorelli & Coello, 2011).

Cross-cultural Considerations

Mainstream early childhood theories are based largely in Western individualistic approaches. Most refugees, however, come from collectivist cultures, with large extended families. They may have a focus on interdependence rather than independence, and compliance rather than self-expression and individual achievement (Reebye et al., 2013), with differences in levels of respect for parents, elders, ancestors and traditions.

Multiple or alternative parental attachment figures are common in many cultures (Signorelli, 2011c, 2014). In some cultures, boys may be favoured above girls to receive educational opportunities and attention (Mehrabiy, Signorelli, & Coello, 2014). In many cultures, children play with each other in open spaces, but not with adults, and may be relatively unsupervised except by older children (Signorelli,

2013b). Praise for the individual may be considered dangerous, a demotivating factor or a threat to pursuing the collective good (Signorelli, 2013a). Feedback from clients, research participants and bilingual staff indicate that some refugee communities do not consider it to be important or appropriate to smile, laugh, engage in public demonstration of affection, sing or play with their child. There may also be different cultural perspectives on what constitutes discipline or abuse (Schaffer, 2011; Signorelli, 2013a). Professionals, therefore, need to be mindful of the fact that a Western way of working in early childhood may be very unfamiliar and requires cultural transition.

Possible Factors Impacting on Refugee Utilisation of Early Childhood Services

This potential mismatch between the Western individualistic basis of research and clinical work, and collectivist patterns of refugee families and communities, may impact on service utilisation (Armin & Shaw, 2011; Bemak, Chung, & Bornemann, 1996; De Anstiss, Ziain, Procter, Warland, & Baghurst, 2009; Kim, 2011). Some refugee families may be reluctant to engage with therapeutic, health related or early childhood programmes (Edwards, 2012; Signorelli, 2011c) because of fear of contamination of traditional values and their world view. Some parents may not perceive the benefits of out-of-home programmes, as these did not exist in their country of origin as noted by Signorelli in observations and discussion with clients. Distrust (Adamson, Warfa, & Bhui, 2011), shame (Kramer, Kwong, Lee, & Chung, 2002) or stigma (Pedersen, Kienzler, & Gamarra, 2010) may prevent engagement in services. Other factors might include guilt, physical, transport or language access issues, diverse perceptions of needs (De Anstiss et al., 2009; McArdle & Spina, 2007), diverse parenting practices, values or expectations of behaviours, obedience (Reebye et al., 2013) or of child development (Ellis et al., 2010; Guzder & Rousseau, 2010; Harkness & Super, 2009; Keller, Voelker & Yovski, 2005; McCubbin, Thompson, Thompson, McCubbin, & Kaston, 1993; Moffic, 2005; Reebye et al., 2013).

Other factors which may impact on underutilisation of services include diverse *idioms of distress* which challenge Western expectations and interpretations (Hinton & Lewis-Fernandez, 2010; Idemudia, 2004; Nichter, 2010), normalisation of trauma symptoms (Hinton & Lewis-Fernandez, 2010; Naw, 2012) and historical and contextual factors, such as previous negative experiences with health workers involved in political repression (Arnault, 2009; Hsu, Davies, & Hansen, 2004; Ussher et al., 2011).

Complex Interactions and Impacts of Refugee Experiences

Refugee and asylum seeker families represent persecuted minorities who have been subjected to human rights violations in the context of organised violence. These include

war, torture, genocide and traumatic loss (Mehrabiy et al., 2014).

The context in which the trauma takes place may determine the child's and parents' experiences of direct trauma, exposure to environmental toxins, loss and lack of adequate access to food, shelter, medical attention and social supports. The young child's direct sensory, emotional and behavioural experiences of trauma may be mediated by the reactions of the care givers, and perinatal stresses in the mother. The child's development will also be affected by normal life cycle issues and developmental stages, and settlement stress.

Crucial traditional extended family support, community structures, roles and support systems have been depleted, fragmented or become non-existent on moving to Australia, creating additional stresses (Schaffer, 2011; STARTTS, 2011). There may also be confusion, suspicion or lack of knowledge about available services, and misconceptions and fears about the role of child protection agencies and authorities (Schaffer, 2011; Yahya, 2013). The child may also experience the effects of domestic violence or child abuse, exacerbated by the parents' own post-traumatic symptoms, traumatic memories, guilt, shame and settlement stressors impacting on emotional engagement and nurturing of the child.

This complex recovery environment is also affected by national and international socio-political events, including continuation of war and conflict in the country of origin, local media and public opinion, and government policies.

Biopsychosocial and Family based STARTTerS Clinical Programme

The STARTTerS multimodal programme integrates interventions that address these challenges and complexities. Objectives for the child include enhancing safety, trauma recovery, development and preparation for transition to pre-school and school. Objectives for the parent include building parenting skill and confidence, and understanding of the child's needs and strengths. Objectives for the parent-child dyad include strengthening attachment and the *social nervous system*, co-regulation and assisting the family's cultural transition. These objectives, and the relevant interventions, interact. In most instances, both the parent and child need tailored interventions. Parents are encouraged to have their own therapy, so they can work through the effects of their own trauma, and enhance their ability to meet the child's developmental needs.

Working with the child-care giver dyad, the therapist uses a mix of structured and unstructured activities and interventions, informed by several modalities. In addition, whenever possible, the therapist engages with the respective communities to plan more culturally appropriate community based education or therapeutic group interventions. The parents or other care givers have the opportunity to develop further skills for use at home and to strengthen their attachment and engagement with their child.

In addition to observations, the STARTTerS programme utilises several assessment tools. These may include the STARTTerS Screening Tool (Signorelli & Coello, 2014a), Greenspan Social Emotional Growth Chart (Greenspan, 2004), Infant-Toddler Symptom Checklist: Long Version (De Gangi & Poisson, 2000), Sensorimotor History Questionnaire for Pre-schoolers (De Gangi & Balzer-Martin, 2000), Parent Survey at commencement and completion (Queensland University of Technology (QUT), Murdoch Children's Research Institute (MCRI), & Playgroup Queensland Sing and Grow Programme (PQS&G), 2009 – modified with permission) and Observation of Interactions Tool (Berthelsen, & Nicholson, 2006). Where more comprehensive assessment is needed, STARTTerS refers children to other health services.

Incorporating Culturally Appropriate Practices in the Early Childhood Programme

The culturally appropriate systemic approach begins with the use of interpreters in the family-centred sessions. The interpreter plays an integral role in communication and as a participant in a small collective community in the sessions, as well as serving as a cultural consultant. Assessment includes gaining knowledge of the family system, structure and roles. STARTTS community consultations and research projects assist in informing the programme about relevant cultural factors and service delivery preferences. The STARTTerS programme also involves collaboration, consultation, cross-referral and case conferences with other services and professionals.

In the STARTTerS programme, consideration of culturally appropriate service delivery influences assessment, intervention, research and community collaboration. It is important to maintain an open attitude in order to learn from the communities about their history, culture and religion, rather than making assumptions. This assists in identification of shared goals for intervention. The STARTTerS clinician takes into account the fact that parents may not easily adopt attitudes, behaviour management or parenting strategies that are taken for granted within a Western framework.

The STARTTerS programme seeks to bridge language differences through the use of bicultural/bilingual workers or interpreters, and the use of bilingual key phrases and words, and relevant written materials, including songs or fact sheets. Where possible, a mix of musical and play activities from both the source culture and Western cultures are used. Parental consent is obtained for the use of specific interventions such as music and dance, which may not play a part in the family's culture. Parents may be invited to attend other STARTTS programmes, including FICT, which includes discussion about customs, legal aspects and child protection issues.

Preliminary Clinical Assessment Data

A preliminary analysis of clinical assessment data in the STARTTerS programme from 2012 to 2015 (Signorelli & Coello 2015) was carried out with regard to 43 children, with consent of the parents. The children were aged between 9 months and 6 years, with an average age of 4 years and 9 months. The children were from various Middle Eastern, African and Asian countries. Fifty-two per cent were girls. Fifty-four per cent had been in Immigration Detention in Australia, and 10% had been in refugee camps.

Initial assessments revealed that 98% of the children had delays or difficulties in at least two domains, and 95% in at least six domains. The domains include physical health, gross motor milestones, sensory processing, dysregulation, emotional development, social development, language and communication development and play. Only 5% showed delays in physical gross motor skills development, but 13.5% had a diagnosis of a medical condition or disability that may have contributed to dysregulation and developmental delays. Thirty-five per cent showed mild to moderate delay in learning. Incidence of problems in all the other domains was very high. Many children showed “patchy” performance or development in social–emotional development, without clear mastery at any level.

Parents’ goals for the child included reducing identified symptoms, improving the child’s relationships with other children, coping with separation and preparing for pre-school or school.

Early reviews of the children in the STARTTerS programme suggested that the greatest improvements occurred in the areas of regulation, social and emotional development, language and communication, play and learning development, and to a lesser extent sensory processing. With a few children, behavioural improvements did not necessarily carry over in the home environment, perhaps reflecting the impact of the care givers’ own post traumatic signs and symptoms or ongoing settlement stresses.

Informing and Enriching the STARTTerS Programme Through Community Based Participatory Research

An ongoing CBPR project, piloted with the Karen and Mandaean refugee communities, is providing greater understanding at STARTTS of how these specific refugee communities perceive the impact of refugee experiences on their nought-to-five year olds, how they prefer to seek help if needed and under what conditions (Signorelli, 2013b). The aim of this study is to better tailor services to meet the needs of these communities. The targeted communities were identified as smaller emerging communities, with fairly high numbers of very young children, and an existing relationship with STARTTS, but with differing trauma histories. They were willing to engage in the process of learning more about the impact of trauma on families with very young

children, and to inform STARTTS about cultural issues and perspectives on these issues.

There are about 1000 Karens living in Western Sydney and Wollongong, with an estimated 12% being very young children (Zu, 2012). The Karen people have been repressed and persecuted in Burma for several decades (Karen Buddhist Dhamma Dhutta Foundation, 2011). They lived in very restrictive refugee camps, in modified tents, without work rights and with poor access to food and other amenities. Possessions were scarce.

The Mandaean population in Western Sydney at 2011 was 8000, of whom 25% are very young children (Satar, 2012), and there has been a large number of new arrivals in 2015. The Mandaean people are a minority group from Iraq and Iran, who have fled to escape from organised persecution and annihilation. Many Mandaeans are highly educated and were very successful business people in Iraq, before the various wars and persecutions robbed them of their possessions and drove them out of their country.

Methodology

The CBPR approach embraces cultural diversity and addresses cross-cultural utilisation issues. It combines strength-based, culturally informed, participatory and power-sharing factors leading to the development of successful public health interventions (Brenner et al., 2005; Ellis et al., 2010; Fitzgerald et al., 1997; Israel, Coombe, & McGranaghan, 2009; O’Fallon & Dearth, 2002). CBPR studies have been carried out in many cultural contexts (Abdi, Ahari, Amani, Habibzadeh, & Yousefi, 2012; Knatterud-Hubinger, Mendenhall, Narr, Solheim, & Velasquez, 2011), to explore service utilisation for adolescents and adults (Collman & Srinivasan, 2005; Commanda et al., 1999; Ellis et al., 2010). These studies did not address specific early childhood issues and services. The CBPR approach has been found to lead to increased service utilisation with consequent improvement in health and well-being (Viswanathan et al., 2004). This model is consistent with the STARTTS systemic model (Aroche & Coello, 1994), and is crucial for building trust with refugees whose traumas are “characterised by powerlessness, in the context of persecution, state terrorism, organised violence and repression” (Aroche & Coello, 1994, p.2).

Methods

Ethics approval for this mixed method study was obtained from the Ethics Committee of the Health New South Wales South West Sydney Local Health District, and the study complied with all ethics requirements.

Participants

The purposive sample of 48 male and female adults from the research project’s target community included parents,

grandparents other care givers, community leaders and other community members.

Data was collected through focus groups, interviews and demographic data. Discussion was enhanced through use of brainstorming and interview techniques, visual prompts, in particular a pictorial version of the STARTTerS Screening tool, and interpreters and translated materials, as needed. Questions were designed to explore perceptions of strengths and challenges for the 0–5 year olds and their care givers here in Australia, and identify changes since coming to Australia. Discussion also explored the participants' goals, and challenges in meeting those goals. Help-seeking preferences and possible collaborative service delivery were explored. The demographic data collected included personal demographics, migration history and visa status, country of origin, countries of asylum and time spent in refugee camps or detention centres.

Results

To date there have been 48 participants, including 19 Karen and 29 Mandaean participants. Thirty-seven per cent of the Karen participants were males, but there were no male participants in the Mandaean sample. None of the Mandaean had been in a refugee camp, although 4% had been in immigration detention in Australia. In contrast, all Karen participants had spent long periods of time in refugee camps.

Between 65% and 100% of participants in both communities identified the presence of potential signs and symptoms of trauma in the 0–5 year olds in their community, across each of the nine health and development domains covered in the pictorial version of the STARTTerS Screening Tool. These domains included physical health, gross motor developmental milestones, sensory processing, regulation, emotional development, social development, language and communication, imaginative play and learning. While both communities identified many possible trauma symptoms in the very young children, they did not seem to have linked them to the stresses associated with their refugee experiences. There was high awareness of parents' settlement and support issues. Ninety-four per cent of Karen participants, and 100% of the Mandaean participants, indicated that the parents/care givers had health and settlement issues that made it difficult for them to spend time with their very young children.

There was variation in ratings of the importance of signs and symptoms, between the two research groups. The Karen research group gave ratings from 25% to 90% for the importance of the different domains, while the Mandaean group gave ratings ranging from 43% to 82%. Both groups gave low ratings for the importance of symbolic play. Fifty-two per cent of the Karen participants rated regulation of behaviour and emotion as important, compared to 85% of Mandaean participants. Thirty-five per cent of the Mandaean research participants considered sensory processing to be important, compared to 43% of Karens. The Karen

participants regarded social and emotional development as less important (64% and 62% respectively) compared to the Mandaean participants (70% and 90%). Some Karen participants recognised the prevalence of sadness and nightmares, but did not perceive them to be as important as behavioural signs. In comparison, 96% of the clinical sample rated sensory processing problems as being very important, and also rated the importance of health, physical development and language and communication more highly than the research groups.

The research groups identified broad goals for the family or community. These included achieving good health, education, retention of the community's language and culture and good behaviour in the children. This contrasted with very specific individual goals that the care givers in the clinical group identified.

To address these community goals, there was strong preference for seeking help from general practitioners, friends, pre-school and counsellors for parents. Lack of knowledge of existing services emerged. Language accessibility was considered important, and there was a slight preference for the use of interpreters over bilingual workers or workers from their own community. Participants expressed interest in group rather than individual interventions, experiential training, information and skills development, to enable communities to provide their own early childhood programmes and family support.

The Karens also expressed strong preference for support from friends, religious elders, pre-school or child care, Centrelink and STARTTS and moderate interest in other services such as playgroups, library and toy library and settlement service organisations. There was a strong preference for "no cost" programmes, and home visits, collaborative activities with STARTTS and activities within familiar venues.

The Mandaean participants expressed moderate interest in seeking support from immediate family, pre-school, playgroup, libraries and toy libraries, parenting support services, legal services and other organisations including STARTTS. They had low levels of interest in accessing extended family support, wider community and religious leaders. Confidentiality and transport issues were very important for this community.

Other emerging factors in the research groups (Signorelli, 2013b) included the tendency to focus on parents' or older children's problems, as well as concerns about stigma, distrust, cultural transition and changes within the communities. Some participants suggested that the consultation be extended to religious and community leaders who could in turn allay concerns about these issues.

Discussion

The perceived high levels of signs and symptoms of trauma are consistent with the literature on the impact and expression of trauma on very young children, and also consistent with the STARTTerS clinical assessment data. The higher

functional areas of playing and learning seemed to be less impacted by trauma in the Mandaean community, as perceived by the parents. This is not what would be expected following a *Neurosequential* approach to trauma recovery (Perry, 2006) in that it might be expected that higher functional levels would not develop well on the basis of delays in earlier functional areas. The perceived challenges that very young Karen children have with reading books, drawing and building with blocks may reflect the fact that the Karen families did not have exposure to books and puzzles and other play equipment when they were living in the refugee camps.

Some potential signs and symptoms of trauma may not be seen as important to the participants because of normalisation of the symptoms (Naw, 2012), or cultural differences in expectations. Other signs and symptoms may be recognised but not understood, such as sensory processing problems and their possible contribution to emotional and behavioural dysregulation.

The broad goals identified by the community members in the research groups possibly reflect concerns about the previous threatened extinction of their community. In contrast, the very specific goals of the parents in the clinical programme may reflect the fact that the families were living with the children's signs and symptoms on a daily basis.

Limited uptake of services may reflect the parents' own traumatic experiences, their reactions to their children's symptoms, their lack of knowledge about appropriate services and the stressors associated with settlement challenges.

One of the limitations of the study was the low number of male participants. Thirty-seven per cent of the Karen sample was men. There were no male Mandaean participants, perhaps reflecting the community structure in which the care of very young children is considered to be primarily the role of the mother. There were also very few recent arrivals included in the study, and little variation in education levels. A larger sample for each community is needed, in order to test validity and reliability of the STARTTerS Screening Tool Pictorial version, to compare the results from each community or to generalise the findings within the target communities. Differences in perceptions between the two research samples indicate that variations occur between cultures, therefore findings cannot be generalised to other communities.

A satisfying outcome of the CBPR project, however, is the development of collaborative planning and development of early childhood programmes that are community based. These include STARTTS' hosting of, and participation, in an existing Karen Supported Playgroup, and development of a Mandaean Early Childhood Planning and Training Group, and Mini-Mandi Playgroup. These group initiatives provide opportunity for screening of children and their families, informal psychoeducation, support or referral to other appropriate services, including the STARTTerS programme. In turn, the communities are assisting STARTTS staff to better understand their community values, aspirations and needs and explore ways to provide integrated services. These ini-

tiatives are also raising the profile of the early childhood age group within their communities.

Recommendations

This study should be continued, and extended to other refugee communities, with a broader mix of gender, length of stay in Australia and community subgroups in order to achieve a more comprehensive representation of each community. A larger sample will enable validity and reliability testing of the STARTTerS Screening Tool Picture Scale, as well as comparative analysis of different communities' perceptions, participant demographics and refugee experiences.

Studies could also explore reasons for low participation of men, difficulty perceiving connections between signs and symptoms with trauma and for variations in importance ratings of specific signs and symptoms. Other cross-cultural studies could include exploration of community structures, child rearing practices and expectations of early childhood development.

Community participation in early childhood interventions could be enhanced by providing training for communities, and collaboration with General Practitioners and other health service providers, to identify and support children who need more help. Provision of clinical group interventions may also increase service utilisation.

Conclusion

The STARTTerS biopsychosocial and systemic early childhood programme serves as a model for collaborative and consultative design and implementation of culturally appropriate services for very young refugees and their families. This challenging and enriching process needs to be tailored to specific refugee individuals, families and communities. The effectiveness of this approach depends on building trust, and a willingness to learn from the communities, and adapt Western methods and approaches appropriately, in conjunction with the families and communities. Systemic programmes can be used to bridge language and cultural differences, build family and community skills and support cultural transition. The sharing of expertise can enhance partnerships and collaborations, through community consultation, research, cross-referral and liaison with other service providers.

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