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In this edition of the Children's Research Digest the focus reflects the theme of our 2016 annual conference, 'Building Resilience, Enhancing Social Support in the Lives of Children and Young People'. The decades immediately preceding and following the turn of the new millennium were largely concerned with mapping the interconnected harms children suffer as a result of poor parental care and degraded social environments. Recent years, however, have witnessed an increased concentration on what needs to be done to either prevent or ameliorate such harms to children. This has become especially important in the light of new evidence that demonstrates the physiological and psychological embedding of early adversity with subsequent consequences for individuals cast over their life-course. This brings huge costs, both to the individuals concerned and to the societies in which they live. In such situations, it is important to attend to the protective factors that may act to buffer an individual from the negative impacts of adversity. Resilience is one such important protective factor and represents the ability to cope and/or adapt to adversity.

Resilience is, however, a somewhat problematic term, as it draws our attention not to the source of the adversities suffered by the individual (the focus of preventative efforts being to stop these occurring in first place), but rather to resources residing within the individual or in their familial and social environments (Ungar, 2013; Masten, 2014). Resilience, it is important to note, is not an exclusively individual trait but is influenced by the individual's social and physical environment. There is therefore an acknowledgement implicit in the term that some adversities will be experienced, and may indeed be necessary for resilience to develop (Rutter et al., 2007; Siegler et al., 2014). Resilience requires a 'balancing act' in that it only develops in situations of controlled exposure to risk and adversity, which means that evading or preventing adversity completely may deprive individuals of building resilience (Seery, 2011). However too much stress and adversity can overwhelm an individual and have a negative impact on their health and well-being, depriving

them of the potential benefits of resilience (Seery, 2011; Hu et al., 2015). Research faces the challenge of identifying this 'perfect balance' and the complex interactions between risk and protective factors for individuals to achieve it.

Our contributors to this edition of the Digest reflect a wide and varied approach to the challenges posed in creating evidence to inform and implement intervention strategies that have the effect of identifying and enhancing resilience in individuals or in their environments, from the familial through to the societal. Our own challenge, as editors, has been to find ways of organising these valuable contributions so as to make a Digest digestible! In the end, we have settled for a life course continuum in which contributions are ordered in ways that reflect stages of development, from the very early years, through school to adolescence and beyond. One of the advantages of this approach is to demonstrate that resilience building is not the preserve of early life interventions, but can be effective for individuals as they age, with each stage of our lives bringing different challenges requiring bespoke age and stage solutions.

We start this exploration into resilience and social supports by turning to research on the social supports for resilience in the early years of life. In "Promoting and supporting the health and well-being of Irish parents and their infants", Ann Stokes et al. examine family demographics, parent characteristics, well-being and parenting experiences in a sample of Irish parents with young infants participating in the Area Based Childhood (ABC) Programme. The article is a summary of the baseline study of the evaluation of the Parent and Infant (PIN) Programme and provides insights into the experiences of parents living in disadvantaged areas. Geraldine Maughan then takes us through a study assessing the effectiveness of Marte Meo Therapy in treating attachment relationships. Marte Meo is a practical intervention that can assist with establishing, re-establishing and supporting attachments between caregivers and their children and thereby helps to build caregivers and children's

future resilience. Shirley Gillespie then guides us through the Toybox Programme developed for Traveller children, aged zero to four years. The programme proves effective in improving long term outcomes for Traveller children, namely that “children are healthy, eager and able to learn and make successful transitions”.

Before we turn to a focus on young people's resilience, a number of articles examine resilience for children of all ages, focused not on age but on particular disadvantages such as disability and autism. Helen Lynch explores the role of outdoor playspaces in building resilience in children with a disability. At present, such children have especially poor access to outdoor playspaces and are therefore experiencing greater risks to their physical and mental health and well-being. Cross et al in turn present a transdisciplinary intervention programme and the effects this has had in building resilience in adolescents with autism spectrum disorder as they transition to adulthood.

We then turn to a variety of initiatives and research studies of resilience and social support for young people from a variety of backgrounds and with diverse experiences. Danika Sharek brings us through her research with transgender young people and their families through which she seeks to develop new educational tools by exploring families' education needs. We stay in the area of education when we turn to Seana Friel's research with higher education students with a care background through which we get a succinct insight into some of the issues faced by these students along with some of the factors that contribute to the young people's educational resilience. We then get an interesting insight into the immense resilience that emerges through young people's meaningful participation in the matters that affect their lives, including in a youth mental health organisation (Aoife Price) and Youth Civic Engagement (Sheila McArdle). Lorna Kerin et al in a similar vein show us the benefits to young people's mental health resilience emerging from being offered a vehicle through which young people with the genetic disorder 22q11.2

Deletion Syndrome can communicate their lived experience and service recommendations to parents, educators, researchers, service providers and policy makers.

Finally, a series of short and digestible research summaries contribute further to our understanding of resilience and social support by taking us through the development of new instruments for assessment and offering summaries of and access to relevant evidence reviews. Several of the research summaries also give us greater insight into children's resilience through a focus on well-being and children's own narratives. We sincerely hope you enjoy this edition.

We would like to thank all authors and the reviewers for their contributions to this issue. Special thanks are also due to all who helped with proof reading and AAD for providing the design and layout. As something new in this edition, authors have been offered to make a contribution towards printing costs to facilitate greater distribution and dissemination of the Digest to appropriate audiences. We thank everyone who contributed.

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References

Centre for Effective Services (2016) *An AcCESs Evidence Report: Childhood Adversity; Learning from research and practice*, Dublin: Centre for Effective Services.

Hu T., Zhang D. and Wang J (2015). *A meta-analysis of the trait resilience and mental health*. *Personality and Individual Differences*, 76, 18-27. doi:10.1016/j.paid.2014.11.039

Masten A. & Monn A. *Child and Family Resilience: A Call for integrated science, practice and professional training*. *Family Relations* 64, 5-21. doi:10.1111/fare.12103

Rutter (2007) *Resilience, competence and coping*. *Child Abuse and Neglect*, 31(3), 205-209. Doi:10.1016/j.chiabu.2007.02.001

Seery M. (2011) *Resilience: A Silver Lining to Experiencing Adverse Life Events?* *Current Directions in Psychological Science* 20(6), 390-394. doi:10.1177/0963721411424740

Siegler R, Deloache J., Eisenberg N and Saffran J. (2014) *How Children Develop*, (3rd ed), United States: Worth Publishers Inc.

Stewart M., Reid G. and Mangham C. (1997). *Fostering Children's Resilience*. *Journal of Paediatric Nursing*, 12 (1), 21-31

Ungar M. (2013). *Resilience, trauma, context and culture*. *Trauma, Violence & Abuse*, 14 (3), 255-266. doi:10.1177/1524838013487805



Promoting and supporting the health and well-being of Irish parents and their infants: some preliminary baseline findings

Ann Stokes, Gráinne Hickey, Yvonne Leckey, Shane Leavy and Sinead McGilloway.

Introduction

Recent years have seen increasing recognition of the importance of prevention and early intervention programmes to support parents, alongside a growing pool of high quality research in Ireland that provides important insights into the lives of children and their families (e.g. Department of Children and Youth Affairs [DCYA], 2014; McGilloway et al., 2014; Nixon, Swords and Murray, 2013). Sensitive parenting has been shown to have a positive impact on a child's cognitive, emotional and physical development (Shonkoff and Phillips, 2000). Conversely, negative and conflicted parent-child relationships and ineffective parenting practices have been linked to maladjusted child developmental trajectories (Capsi et al., 2004; Lorber and Egeland, 2011).

The birth of a child can bring much happiness and enjoyment in new parents' lives, but can also lead to significant stress and disrupted family relationships. Parental resilience in the face of parenting stressors is important. The psychosocial health of parents and the ability of parents to create home environments characterised by social, emotional and cognitive support constitute important protective factors in the lives of children. More positive transitions to parenthood may help to bolster parental self-confidence and encourage the acquisition of more effective parenting skills, whilst also protecting against depressive symptoms, stress and anxiety (Kohlhoff and Barrett, 2013; Leahy-Warren and McCarthy, 2011). Positive parental adjustment during this vulnerable period can also contribute to the development of positive parent-child relationships, thereby providing a sound basis for healthy child behavioural and socio-emotional development into the future (Overbeek et al., 2007; Serbin and Karp, 2004).

This study examines parental adjustment over the first two years of an infant's life. The research outlined in this paper was conducted as part of a larger evaluation of a new community-based, early parenting intervention, the Parent and Infant (PIN) programme, which aims to improve

parenting competencies and infant outcomes in the earliest years of life. The PIN programme is a wraparound-inspired, prevention and early intervention model delivered by Public Health Nurses (PHNs) in collaboration with community-based services. The intervention combines a range of developmentally-appropriate parent and infant supports, including the Incredible Years (IY) Parent and Baby and Parent and Toddler programmes (Webster-Stratton and Reid, 2008); Baby Massage; paediatric first-aid training and other workshops, which are delivered in a single intervention process from birth to two years of age. The PIN programme is part of the new Area Based Childhood (ABC) Programme in Ireland (DCYA, 2013) which involves the implementation of 13 area-based approaches to prevent and reduce child poverty in socially deprived areas. Two of these - the Blue Skies Initiative in Clondalkin and the Genesis Programme in Drogheda/Dundalk - are currently delivering the PIN programme as one of a number of services in their area-based approaches. This paper provides a brief description of the health and wellbeing of parents with very young infants who are participating in a non-randomised controlled-trial evaluation of the PIN programme. The aim of this current study was to assess parental characteristics and self-reported experiences of parenting during infancy, with a focus on the first two months of life.

Methods

Participants and settings

The study was conducted in Dublin South West and Drogheda/Dundalk, Co. Louth. Both are urban areas that include neighbourhoods characterised by significant socio-economic disadvantage such as high rates of early school leaving and lone parent families (Fleming and Gallagher, 2004; Haase and McKeown, 2003; Louth Children's Services Committee, 2012). Participants were eligible for inclusion if they: (a) were aged 16 years or older; (b) had an infant aged 6-20 weeks; (c) were willing to participate in the study; and (d) were able to communicate

in English. Mother-infant dyads were recruited to the study via community-based health clinics and community-based child and family services. Mothers were recruited on a phased basis during December 2014–June 2016. A total of 239 agreed to be contacted, 190 of whom (79%) provided written informed consent to participate in the research (Figure 1).

Measures

Demographic and background information on all families (e.g. age, marital status, living arrangements, employment status) was collected using a Profile and Demographic Information Form (PDIF). Additional information was obtained on the general health and relationships of the principal carer and family members, perceived stress, and difficulty with routine care activities using items adapted from the Growing Up in Ireland Study (Thornton et al., 2013). The Parental Sense of Competence (PSOC) scale (Johnston and Mash, 1989) was used to assess parental self-efficacy and parent satisfaction, whilst maternal depressive symptoms were assessed using the Patient Health Questionnaire-9 (PHQ-9; Spitzer et al., 1999).

Results

The average age of mothers at baseline (at the birth of the index child) was 31.6 years (SD=5.4), compared to 34 years (SD=5.5) for fathers. Over half (55%) were first time mothers, almost one-quarter were lone parents or living apart, whilst approximately one in five (19%) were non-Irish nationals (Table 1). Educational attainment was generally high with most participants having completed at least post-primary education (89%) and in full-or part-time employment (71%). However, one-third of the sample had a household income of less than €24,000 per annum (33%), whilst 18% were deemed to have children who were 'at risk' of developing conduct problems at a later date (calculated using a 'risk factor score' based on, single parenthood, teenage parenthood, parental depression, family poverty, and parental history of drug abuse or criminality (Webster-Stratton, 1998).

Infants comprised roughly equal numbers of boys and girls who were almost two months old when assessments were conducted. The self-reported health of participants and their infants was in the main very good; most mothers reported no health problems or only minor illness for themselves (36%) and their infants (19%). Significant illnesses were reported for only seven parents and two infants. Almost half of the sample (48%) reported at least some stress due to looking after their baby. Approximately one third (28%) reported minor difficulties with routine baby care activities, whilst a further 14% reported 'moderate' to 'large' difficulties coping with their baby's sleeping and crying patterns. A further 19% of participants reported having worries or concerns about their baby's health or behaviour, which most commonly included excessive crying/colic, sleep-related problems, health issues and reflux or feeding problems.

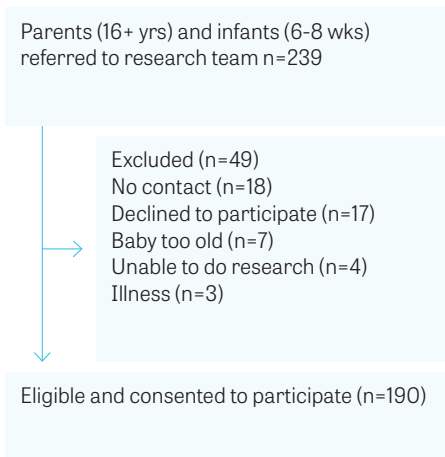


Figure 1: Participant Flow Chart

Variable	n (%)*
Single/Living apart	42 (22)
First time mother	105 (55)
Mean age of mothers	31.6 (SD = 5.4)
Teen parent at birth of first child	15 (8)
Partner mean age	34 (SD = 5.5)
Infant mean age in months	1.9 (0.8)
Boys	91 (48)
Left school before finishing post primary	21 (11.1)
Both parents working (full/part-time)	134 (71)
Neither parent working	10 (5)
Low family income (under €24,000 per year)	62 (33)
Risk factors for child conduct disorder score (Mean, SD)	0.7 (SD = 1)
Risk factors of conduct disorder, percentage over 2	35 (18)

Table 1: Family Characteristics

*n = number of participants; % = percentage of participants

Mothers reported typically low levels of depressive symptoms (PHQ-9); only 3% (n=5) reported moderate to severe depressive symptomatology. Scores on the PSOC scale indicated generally high levels of parental self-efficacy, which are important in protecting against parental stress and poor quality parenting, as well as poor infant developmental outcomes (Goodman et al. 2011; Hess, Teti and Hussey-Gardner, 2004). However, a substantial minority of parents reported moderate to low levels of parenting satisfaction and self-efficacy (Table 2).

Most parents reported 'good/very good' relationships with their partner and/or wider family circle, as well as a high level of support from family and friends (Table 3). Most participants reported feeling closer to their partner after the birth of the index child, whilst father involvement in the upbringing of their child was reported as high. Most parents had attended a GP and/or seen a nurse or midwife in the weeks after leaving hospital. However, 12% of parents reported no contact with any health or social service professionals regarding their own health and well-being since leaving hospital (Table 3).

Variable	n(%)*
Self-reported maternal health	
Good health	114 (60)
Minor health problems	69 (36.3)
Quite Ill/Unwell	7 (3.7)
Parent-reported Infant health	
Good health	115 (79.5)
Minor health problems	37 (19.5)
Quite Ill/Unwell	2 (1.1)
Stress due to looking after baby	
"Not much"	34 (18)
"Some/A great deal"	58 (31)
Difficulty with routine baby care	
"Minor difficulty"	54 (28)
"Moderate-Large difficulty"	27 (14)
Concerns/worries regarding baby (e.g. health, behaviour)	37 (20)
PHQ-9 Mean score	3.7 (SD=3.9)
Minimal - Severe symptomology	15 (8)
PSOC Mean score	74.7 (SD=9)
Moderate – Low sense of competence	53(28)

Table 2: Parent and (parent-reported) Infant Health (Numbers are figures (%), unless otherwise indicated)

*n = number of participants; % = percentage of participants

Variable	n (%)*
Father highly involved in upbringing of baby	152 (80)
Very good relationship with partner	130 (68) [†]
Relationship with partner closer post-birth	101 (88) [†]
Very good relationship with wider family	126 (66)
Argue with partner less than once a week	95 (64) [†]
Argue with partner over upbringing of baby less than once a week	128 (86) [†]
High support from family and friends	116 (61)
Mean (SD) no. of contacts with health/social care professionals regarding own health and wellbeing since leaving hospital	3.4 (SD=3.6)
Mean no. of contacts with GP	1.4 (SD=1.8)
Mean no. of contacts with nurse/ midwife	1.1 (SD=1.9)
Mean no. of contacts with other	0.9 (SD=1.7)
No contact with health/social care professionals regarding own health and wellbeing since leaving hospital	23 (12)

Table 3: Parent support and service utilisation (Numbers are figures (%), unless otherwise indicated)

*n = number of participants; % = percentage of participants;
[†] Percentage given for total number of partnered parents (n=148)

Discussion

The post-natal period can be a time of considerable vulnerability and stress for parents. This study examined family demographics, parent characteristics, well-being and parenting experiences (e.g. parenting-related stress, difficulty with routine baby care activities and parental self-efficacy) in a sample of Irish parents with young infants in the ABC Programme. Overall, the findings paint a generally positive picture of parental and child health and well-being in the earliest months of a child's life, with most parents reporting good health, low levels of depressive symptoms and high levels of social support as well as typically low levels of parenting-related stress and a high sense of parenting competence. However, a sizeable proportion experienced stress in their parenting role, and our findings also suggest the existence of one or more potentially vulnerable sub-groups including the significant minority (almost 20%) who reported considerable difficulty in managing their baby's care as well as lower levels of parent satisfaction and self-efficacy (28%). For instance, contextual stressors such as parents living in disadvantaged areas and lone parenthood led to a decreased sense of competency.

This baseline study provides interesting insights into the lives of parents living in mainly disadvantaged areas in Ireland who are providing care to young infants. Further assessments will be undertaken when children are 8, 16 and 24 months old in order to assess parent and infant outcomes over time, as well as the impact of prevention and early intervention services (the PIN programme) on family health and wellbeing. The sub-groups who are faring less well, including the 17% of infants deemed to be at risk of conduct problems, will also be monitored closely. Additional process evaluation and economic data will be used in the ongoing work to establish the overall effectiveness of the new PIN service model and to identify key lessons for other areas of service provision. It is anticipated that the findings will make an important contribution to the development

and implementation of community-based early parenting interventions designed to promote positive parent-child relationships and build resilience in the earliest years.

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References

- Caspi A., Moffitt, T.E., Morgan, J., Rutter, M., Taylor, A., Arseneault, L., Tully, L., Jacobs, C., Kim-Cohen, J. and Polo-Tomas, M. (2004) Maternal expressed emotion predicts children's antisocial behavior problems: using monozygotic-twin differences to identify environmental effects on behavioral development, *Developmental Psychology*, 40, pp.149-161.
- Department of Children and Youth Affairs (2013) Area based response to child poverty program 2013 – 2016. Dublin: Government of Ireland.
- Department of Children and Youth Affairs (2014) Better outcomes: Brighter futures. Dublin: Stationary Office.
- Fleming, T. and Gallagher, A. (2004) In trouble from day one: Children in Clondalkin with emotional and behavioural difficulties: A community response. <http://eprints.maynoothuniversity.ie/985/> (2004). Accessed 31 Jan 2017.
- Goodman, S.H., Rouse, M.H., Connell, A.M., Broth, M.R., Hall, C.M, and Heyward D. (2011) *Maternal depression and child psychopathology: a meta-analytic review*, *Clinical Child and Family Psychology Review*, 14, pp.1-27.
- Haase, T. and McKeown, K. (2003) *Developing disadvantaged areas through area-based initiatives. Reflections on over a decade of local development strategies*. Dublin: Area Development Management. www.lenus.ie/hse/bitstream/10147/287311/1/DevelDisadvantAreas.pdf. Accessed 31 Jan 2017.
- Hess, C. R., Teti, D. M., and Hussey-Gardner, B. (2004) *Self-efficacy and parenting of high-risk infants: The moderating role of parent knowledge of infant development*, *Applied Developmental Psychology*, 25, pp.423–437.
- Johnston, C., and Mash, E. J. (1989) *A measure of parenting satisfaction and efficacy*, *Journal of Clinical Child Psychology*, 18, pp. 167-175.
- Kohlhoff, J. and Barrett, B. (2013) *Parenting self-efficacy links with maternal depression: infant behaviour and adult attachment*, *Early Human Development*, 89, pp. 249-256.
- Leahy-Warren, P. and McCarthy, G. (2011) *Maternal parental self-efficacy in the post-partum period*. *Midwifery*, 27, pp. 802-810.
- Louth Children's Services Committee (2012) *Children and Young People's Plan 2012 – 2014*. <http://www.cypsc.ie/fileupload/Documents/Resources/CYPP/Louth%20Children%20and%20Young%20People%E2%80%99s%20Plan%202012%20to%202014.pdf>. Accessed 31 Jan 2017.
- Lorber, M.F. and Egeland, B. (2011) *Parenting and Infant Difficulty*, *Child Development*, 82, PP. 2006-2020.
- Serbin, L.A. and Karp, J. (2004) *The intergenerational transfer of psychosocial risk: mediators of vulnerability and resilience*, *Annual Review of Psychology*, 55, pp. 333-363.
- McGilloway, S., NiMhaille, G., Bywater, T., Leckey, Y., Kelly, P., Furlong, M., Comiskey, C., O'Neill, D. and Donnelly M. (2014) *Reducing child conduct disordered behaviour and improving parent mental health in disadvantaged families: a 12-month follow-up and cost analysis of a parenting intervention*, *European Child & Adolescent Psychiatry*, Vol. 23(9), pp. 783-794.
- Nixon, E., Swords, L. and Murray, A. (2013) *Parenting and Infant Development*. Dublin: Department of Children and Youth Affairs.
- Shonkoff, J.P. and Phillips, D.A. (2000) *From Neurons to neighbourhoods: The science of early child development*. Washington, DC: National Academy Press.
- Spitzer, R.L., Kroenke, K. and Williams, J.B.W. (1999) *Patient Health Questionnaire Study Group. Validity and utility of a self-report version of PRIME-MD: the PHQ Primary Care Study*, *Journal of the American Medical Association*, 282, pp. 1737-1744.

Thornton, M., Williams, J., McCrory, C., Murray, A. and Quail, A. (2013) *Design, instrumentation and procedures for the infant cohort at wave one (9 months)*. Dublin: Department of Children and Youth Affairs.

Webster-Stratton C. and Reid MJ. (2008) *The Incredible Years Parents, Teachers and Children training series: A multifaceted treatment approach for young children with conduct problems*, p.194-210 In Weisz J and Kazdin A (eds) *Evidence-based psychotherapies for children and adolescents*, 2nd edition. New York: Guilford Publications.



An exploration of the value of Marte Meo Therapy in establishing, re-establishing and supporting attachment relationships

Geraldine Maughan

Introduction

The effectiveness of Marte Meo Therapy (MMT) in treating attachment relationships has not yet been researched in Ireland. The purpose of this qualitative study was to explore what role, if any, MMT has in establishing, re-establishing and supporting attachments between caregivers and their children. Pertinent previous work and current thinking on attachment theory was reviewed and suggested approaches in which the Marte Meo method may provide a practical application of this theory. MMT and attachment will be briefly outlined. It will then be discussed how MMT can assist caregivers form attachments with their children. However, MMT should not be assimilated into attachment theory or any other theories without further research.

Marte Meo

Maria Aarts (1996) developed the Marte Meo method in 1987. The words Marte Meo are selected from the Latin 'Mars Martis' to express the idea of "on one's own strength". The name was chosen with the intention of highlighting the central focus of the method, which is to firstly identify and then activate and develop caregivers' skills, which enable and enhance constructive interaction and development between caregivers and their children. MMT is deemed a communications approach to child development, which focuses on the quality of interaction between child and caregiver. Situations are filmed and then analysed second-by-second to identify points in the communication where changes may be affected to improve child caregiver interactions and also answer the caregiver's question, which is frequently around behavioural interactions such as "how do I get my child to listen or take direction?" Usually, this question is the caregiver's means of asking "how do I connect with my child?" which is often the primary reason for the intervention.

The focus of MMT has expanded in recent years. Initially it was intended as a short-term support to parents experiencing difficulties coping with their young children's behaviours; currently MMT

is incorporated into various daily living situations to support placements such as children and caregivers in foster, adoptive and residential care situations. In this way MMT is also a solution focussed method that identifies the caregiver's current level of functioning and builds on this by providing the caregiver with opportunities from their film to practise, one step at a time. In this way, MMT aspires to develop the competence of caregivers leading to enhancements to the quality of life for their family by supporting the social, emotional and communication development of their children. This is where MMT is perhaps most powerful as the focus of the intervention is always on the child's development, with the competence of the caregiver developing in tandem with the child. Further enhancements for both the child's and caregiver's resilience can be observed when they realise change came about because of their own strength.

Following moment-by-moment video analysis of their interactions, information is conveyed to the caregivers, which can be incorporated into the individual's unique mode of communicating. These approaches are concerned with developing both emotional literacy and intelligence along with new ways of helping children to express and understand their feelings, form secure attachments, build resilience and relate in caring and responsible ways to others. In other words, caregivers are developing based on what is shown from the analysis of "their own strength". The aim of MMT is for caregivers to connect with their children in ways that break the adverse models that frequently have been learned by intricate childhood experiences in the past and build new possibilities for the next generation. In the words of Bowlby (1988, p.1),

Successful parenting is a principal key to the mental health of the next generation.

Attachment

Attachment has been defined by Fahlberg (1988, p.13) as "an affectionate bond between two individuals that endures through space and time and serves to join them emotionally".

Howe et al. (1999) believes attachment theory has emerged as being invaluable within the framework of assessing children's needs. Attachment theory research affords a vital developmental framework for making sense of the behaviours and relationship strengths and difficulties that children bring from their intricate backgrounds. It also offers a valuable resource for understanding the kind of caregiving that can enable children to feel more trusting, positive, and capable and secure (Fahlberg, 1994). It is fundamental that those providing therapeutic interventions to families support the development of stronger caregiver child relationships. Often this means facilitating the enhancement of a fragile or damaged caregiver child attachment or facilitating a child to connect emotionally with new carers. It is vital that those involved in making decisions around the lives of children and their families have at the very least a basic understanding of attachment theory.

Methodology

A qualitative approach was used for this study. Two focus groups and three semi-structured interviews were convened with Marte Meo therapists, employed as social care workers, social workers, psychologists and public health nurses. The aim was to elicit rich descriptive data from their perspectives on what role, if any, MMT has in establishing, re-establishing and supporting attachments between caregivers and their children. Interpretive Phenomenological Analysis (Smith, 2004) was the approach adopted to analyse the collected data.

Findings

Interviewees and participants believe that once MMT is able to itemise the elements of a good attachment from what they can see in daily interaction moments, coupled with understanding the concrete elements of MMT, MMT supports caregivers to have improved attachment relationships with their children. In Focus Group A, one participant stated that

[Marte Meo] is a practical translation of attachment theory. I can actually see that in interaction every day with parents when you give back information you're not just speaking, you're nailing it down to nitty gritty stuff with the stills but you're bringing your own experience and skills with you.

Another Focus Group A participant believed that

It is around how she actually starts to see her son and begin to notice all the little things he does and how she can be in his world and I think in terms of attachment that's what Marte Meo is good at, showing how parents are in their children's world and what they do that does help their child but also where the gaps are. It really gives us a very clear picture of what's going on for the child.

For two interviewees, MMT and attachment theory complement each other. One interviewee claimed that she does not understand attachment theory. This interviewee stated that she is informed from practice not from theories and then went on to say that

What I did with the problems [caregivers questions] was make all abstract information concrete, understandable and useful to parents and people working with these sorts of problems. I don't know so well [attachment] because I don't study theories...

Participants in both focus groups and three interviewees recount times they have applied MMT with attachment issues, when there is a child who would be regarded in a family as difficult or isolated, possibly because of a diagnosis or lack of availability of the caregiver and they would see that as an attachment piece. All participants noted that when beginning MMT it is at the therapist's orientation [the caregiver's question] but as the work progresses from the first film it is possible to see the child's attachment experiences with their caregiver, increasing the possibility of answering the caregiver's question. Furthermore, in terms of attachment it is believed that MMT is good at showing how caregivers are in their children's

world, what they do that helps their child and also where the gaps are. It gives them a clear picture of what is going on for the child.

In Focus Group A, one participant articulated

In terms of attachment it [Marte Meo] can be very powerful.

Seven out of nine focus group participants and all three interviewees stated the significance of the therapeutic relationship: developing through activating dialogue particularly around the caregivers' beliefs and ideas about their children and eventually and slowly about their own experiences of being a child and that this assists the caregiver's to come into their child's world. One interviewee for example stated that

Anyone can give you information it's how its given, how you connect with the parent and what happens in the review process that is part and parcel of the development of the therapeutic relationship for that parent, where the parent can feel very confirmed, listened to, can feel they have a very real space.

Discussion

The success of MMT may well rely on the relational abilities and experiences of the MMT, rather than any specific theories. The findings suggest that MMT clearly supports caregivers to form attachments with their children throughout the developing therapeutic relationship between caregiver and therapist; through the information given to caregivers from the analysis of their film and through the selection of pictures, which allow caregivers to "see" their child and enter the child's world, often for the first time.

MMT would benefit from a larger scale study before being assimilated into attachment theory. As the findings suggest, it is a practical intervention that can assist with establishing re-establishing and supporting attachments between caregivers and their children. It would seem that participants incorporate attachment theory but ultimately work in their own unique way to answer caregivers' questions. This in

turn builds caregivers' and children's future resilience; caregivers now know the strengths within themselves to resolve relational issues between themselves and their children. Children now know how to activate their caregivers' positive responses to them. The orientation of the MMT may be condensed or diverted from the caregiver's question due to consciously incorporating attachment theory into MMT.

Author information

Having received my Social Care qualification from DIT in 1993, I attained a certificate in Counselling, Psychology and Psychotherapy in 1994. In 1997, I became an accredited Marte Meo Therapist. I was awarded an MA in Therapeutic Child Care in 2008 and Post-Graduate Diploma in Higher Education in 2014. I am currently enrolled as a PhD candidate at TCD. From 1992 until 2013, I worked in both Residential and Community services for young people and families. From 2008 until the present, I have lectured on Social Care and Early Childhood programmes at Carlow College, Carlow IT and presently at LIT. I have presented at conferences at TCD, QUB, Dublin, Malta and Hawaii, resulting in two publications.

References

- Aarts, M. (1996) *Marte Meo Guide*. Aarts Harderwijk, The Netherlands: Aarts Productions.
- Bowlby, J. (1988) *A Secure Base: Clinical Applications of Attachment Theory*. London: Routledge.
- Fahlberg, V. (1988) *Fitting the Pieces Together*. London: BAAF.
- Fahlberg, V. (1994) *A child's journey through placement*. London: BAAF.
- Howe, D. (2000) 'Attachment Theory' in Davies, M. (ed). *The Blackwell Encyclopedia of Social Work* Oxford: Blackwell (pp 25-27).
- Smith, J.A. (2004) *Reflecting on the Development of Interpretative Phenomenological Analysis and Its Contribution to Qualitative Research in Psychology*. *Qualitative Research in Psychology*, vol.1, pp.59–54.



Outcomes of an early childhood development programme for Traveller children

Shirley Gillespie

Introduction

Early Years – the organisation for young children has established the Toybox Programme for Traveller families with children aged 0-4 years, which has a focus on inclusion and combating educational under-achievement. The Programme arose from the organisation's value base, as well as from the identified needs of Traveller families and the Northern Ireland policy context.

This early childhood programme, funded by the Department of Education (NI), aims to improve long term educational outcomes for Traveller children and their families, namely that children are healthy, eager and able to learn and make successful transitions. It is delivered by nine staff to eight areas across Northern Ireland. A Toybox service design manual was developed in 2014 to support and assist Toybox staff and a range of agencies in implementing the Toybox Programme and create effective partnerships with families which incorporate the following key components:

- 1 An outreach home visiting service aimed at empowering Traveller parents to support their young children's optimal development.
- 2 An access programme aimed at supporting the inclusion of Traveller children and parents in SureStart, preschool and primary schools.
- 3 An advocacy programme, including a partnership approach with a range of key stakeholders, aimed at improving policies and services for Traveller children and families.

Description of Services

The service design manual lists the components, which make up the intervention programme and describes what needs to be put into place under each component. The sustained development of Toybox is directly informed by its logical framework, which has directed inputs and processes that moderate predicted outputs, outcomes and impacts. The framework provides a step-by-step approach to working with

stakeholders, including children and parents, and identifies strategies, which provide real benefit to children and families. It also identifies the relationship between each component, which leads to the achievement of expected outcomes.

Component one (Home visiting)

The HighScope evidence and practice model (The HighScope Perry Pre-school study 1962-1967) and Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1979) shape the outreach home interventions delivered through the programme. HighScope is "an evidenced-based approach to early childhood care and education which has been shaped and developed through research and practice over a forty year period" (The HighScope Perry Pre-school study 1962-1967). The HighScope approach was designed by David Weikart and colleagues in 1962, in response to the persistent failures of high school students from Ypsilanti's poorest neighbourhoods. Hohmann and Weikart (1995:3) stated that the low scores, of some students, on academic and intelligence tests were due to a lack of educational opportunities, inadequate school preparation, and low attendance in school rather than a lack of intelligence.

The outcomes of the HighScope programme are relevant and can be applied to Traveller children and their families. For example, children develop positive attitudes to self, others and to future learning and when parents are empowered and involved in their children's education. Toybox staff use the HighScope Adult/Child interaction play strategies to build supportive relationships with children in partnership with parents. They carefully select natural materials and build on children's individual strengths and abilities, scaffolding their interests to become independent creative thinkers. Staff also use the HighScope Child Observation Record (COR) Tool as a method to plan, track, assess and improve outcomes for children and their families. This method guides staff to pinpoint support best suited to the child's needs to help them become healthy, eager and able to learn and make successful transitions. This consistent support,

provided to parents by Toybox staff, embed knowledge and skills that enable parents to become confident facilitators in their children's learning and development.

Using Bronfenbrenner's Ecological Systems Theory, the Toybox programme draws on the conceptual framework of the child in the context of their family and community. This theoretical framework explains how everything in a child's social system impacts positively or negatively on their growth and development. Toybox works continuously with children, families and communities to improve collaborative interactions between all those individuals involved in children's care and development so that positive outcomes for children are achieved.

Component two (Transition)

The Media Initiative for Children Respecting Difference Programme (MIFC) developed by Early Years, in partnership with US-based Pii (Peace Initiatives Institute; Connolly, Miller and Eakin, 2010) is used in the Toybox Programme to help children explore feelings and emotions around transition. The MIFC pack contains persona dolls, which helps the child establish a connection between themselves and others and is important in supporting Traveller children to make the transition from home to early years settings.

Component three (Advocacy)

The participatory nature of engagement by staff with families means that they actively listen to parents and children, through observations recorded by staff. The programme monitors and evaluates the child and the parent's development and continuously assesses parents as strong first educators and children as more resilient and visible in their community. This positive engagement by staff with children, parents and policy makers means that families are regularly and consistently engaged in advocacy strategies.

Methodology of evaluation

The programme is evaluated through a mixed method approach. There is a strong qualitative emphasis, with a focus on engaging stakeholders in a participatory approach. The findings are strengthened by a comprehensive and detailed analysis of quantitative information associated with programme outputs. This involves combining primary data collection in the form of interviews, focus groups and case studies alongside existing monitoring and evaluation data. Together these offer a valuable resource to the programme processes and have been subjected to a detailed and exhaustive analysis in two comprehensive evaluations in 2007 and 2016.

Findings

Information here pertains to the programme evaluation conducted (Collins, 2016) to document trends across the timeline of service delivery on the key components. A number of key quantitative and qualitative component indicators were selected for focused analysis.

Component one (Home visiting)

Individual learning plans have reflected the variability in support systems required for the variety of children's abilities and needs. Toybox staff have demonstrated through their ongoing HighScope recording of observations, taken during play sessions, that Traveller children have improved across developmental domains that suggest progression in terms of social, emotional, physical, cognitive and communication development. Anecdotal evidence and review of ten individual HighScope COR booklets suggested that children are reaching developmental milestones, as tracked by HighScope developmental indicators measured within COR. In questionnaires, which used this format, inspection of the summaries suggested a high degree of parental confirmation about observed improvements across all indicators.

Component two (Transition)

Staff across both pre- and primary settings are in consensus that Traveller children supported by Toybox are eager and able to learn, participative in settings, responsive to learning, and confident in engaging in quality play. A DVD entitled "My Child" completed in 2010 and revisited in 2014 captures the many positive experiences children and families have had in transition to education through initial engagement in the Toybox Programme. These interviews and observations capture the programme impact through the voices of parents and children, which has been achieved through a consistent approach to service delivery.

Component three (Advocacy)

Toybox has been both an advocacy tool and enabler by empowering parents to be 'change agents' in their own right. As a result, the voices, views and experiences of Travellers have informed the development of the following policy strategies: the Traveller child in education 'Action Framework' (2012) and Delivering social change through childcare: A ten year strategy for affordable and integrated childcare (2015-2025). Toybox continues to be a liaison bridge between families and external organisations.

Conclusions

The HighScope evidence and practice model programme, which is driven by the philosophy that children learn by doing, is embedded in the Toybox logical framework. The evidence gathered through HighScope, COR, parent reports, and setting feedback, all point clearly to children demonstrating that they are eager and able to learn and these outcomes are linked with the structure, ethics and processes of the programme.

Within the thirteen-year life span of the project there have been many valuable lessons learnt. Maintaining a focus on the programme's logical framework and key performance indicators has ensured staff remain focused on service integrity and make evidence-informed decisions. Using standardised tools, such as the Child

Observation Record with the Participatory Evaluation approach to gathering evidence, ensures that strong evidence-based outcomes are collated. Good communications between staff, children and parents have ensured that the programme meets the needs of children and families in a respectful way. The programme maintains fidelity to the underpinning ethos of Bronfenbrenner's theory and the HighScope learning approach. The Toybox programme continues to deliver on family driven and culturally appropriate outcomes with the child at the centre of all decisions and actions.

For further information on the Programme and to access the evaluation, please visit: <http://www.early-years.org/toybox/>

Author information

I received a Bachelor of Education (B.Ed.) qualification in 1993. From 1993 to 2003, I taught within the early years sector in England, primarily vulnerable inner city children. For the last thirteen years, I have worked with Traveller families across Northern Ireland. My experience includes delivering outreach home visiting services to families. My most current role is managing staff within this role and overall responsibility for the development and delivery of the Toybox Programme. As a mother of a seventeen year old autistic son, I developed a range of skills in this field which have successfully supported him grow into a confident young adult.

References

- Bronfenbrenner, U. (1979) *The Ecology of Human Development*, Cambridge; Harvard, University Press
- Collins, K. (2016) *External Evaluation of Toybox Project*. Unpublished.
- Connolly, P; Miller, S; and Eakin, A; (2010) *A Cluster Randomised Trial Evaluation of the Media Initiative for Children: Respecting Difference Programme*, Belfast: Centre for Effective Education. Queen's University Belfast. Available at: <http://www.qub.ac.uk/cee/>

Department of Education (2012) *Every School a Good School: Traveller Child in Education Action Framework*. Government of the United Kingdom.

Early Years – the organisation for young children (2014) *Toybox Service Design Manual Early Years Toybox 'My Child'* DVD, www.early-years.org

Hohmann, M and Weikart, DP (1995) *Educating Young Children Active Learning Practices for Preschool and Child Care*. Ypsilanti: HighScope Press.

McVeigh, Robbie (2007) *Early years development through play for Traveller children – an evaluation*. An Dúchán. <http://www.early-years.org/toybox/toybox-evaluation.pdf>

Office of the First Minister and Deputy First Minister (2015) *Deliver Social Care through Childcare 2015-2025. A ten year strategy for affordable and integrated child care*. Office of the First Minister and Deputy First Minister (OFMDFMNI)

The HighScope Perry Pre-school Study <http://www.highscope.org/content.asp?contentid=219>



Playspaces: Children with disabilities and social inclusion

Helen Lynch

Introduction

The occupation of play has a special place in children's lives as it underpins well-being, health, and development of children, and is influenced by their social, cultural, and political worlds (Lynch and Moore, 2016). From a rights-based perspective, all children have a right to play, rest and leisure under Article Thirty-One of the UN Convention on the Rights of the Child (CRC, 1989). Under Article Two of the CRC, children with disabilities are equally entitled to enjoy this right without discrimination. However, children with disabilities are frequently excluded from play, in particular from accessing and using outdoor playspaces, denying them their full enjoyment of their rights. Thus, play provision becomes an issue of social in/exclusion and social support in such instances requires us to consider how best to address provision for outdoor play to promote social inclusion.

In 2016, the Department of Children and Youth Affairs has established a review of the Irish Play Policy, which was first instituted in 2004 (National Children's Office, 2004). At that time, it was stated that the focus in Irish policy was generally limited to physical accessibility for children getting to and from a playground, with no guidelines in existence on usability of playgrounds for all children (Webb, 2003). This paper outlines findings from five recent studies that have been carried out, to see what, if anything, has changed since 2004: to explore play provision in community settings in order to establish the state of play in particular for children with disabilities in Ireland.

Background

While it is acknowledged that play is fundamental for children, playing outdoors is particularly important as a focus of research. In this field of study, outdoor playspace is the term used to encompass all outdoor areas where children play: including local parks, playgrounds, natural community places, school yards and gardens. Outdoor play has a significant role in children's general health and well-being, partly because

of the connection with nature, which strongly impacts on physical and mental health of children, especially when allowed to play freely (Gill, 2014). Contact with nature helps people recover from stress (Ulrich, 1991; Wells and Evans, 2003) and is self-restorative for children (Korpela, Ylen, Tyrvaïnen, and Silvennoinen, 2008), while spending time in nature promotes better attention and decreases symptoms of ADHD (Taylor, Kuo and Sullivan 2001; Kuo and Faber, 2004). Studies have reported positive effects on children from playing in natural environments (Fjortoft and Sageie, 2000). This is partly attributed to the flexibility of outdoor playspaces where there are larger spaces for movement alongside the availability of moving parts. Not surprisingly, access to the outdoor environment has been identified as a significant predictor of physical activity (Sallis, Prochaska, and Taylor, 2000). Furthermore, outdoor playspaces are known to be important sites for social learning (Beunderman, 2010) and in general, are sites for social inclusion (Prelowitz, 2007). Playing can overcome cultural and social boundaries and enables children to understand others who they might consider different from themselves (Burdette and Whitaker, 2005).

However, researchers in other countries have found that children with disabilities experience significantly reduced participation in play (King et al., 2009) and are at risk of health and social difficulties (Kolehmainen et al., 2011). They are often excluded from outdoor play due to many factors such as physical inaccessibility, attitudinal barriers, and poor social supports (Anaby, et al., 2013). In studies of participation of children with coordination difficulties such as Cerebral Palsy or Developmental Coordination Disorder, research shows that attitudinal barriers are more prevalent than barriers due to the physical environment (Poulsen, Ziviani and Cuskelly, 2007; Anaby et al., 2013). The child's own skills can contribute to difficulties in participating in outdoor play on an equal basis with others. For example, children with physical disabilities can have limitations in movement which further limits participation in play (Law et al., 2004),

while many children with Autism Spectrum Disorder experience significant difficulties in sensory processing that impact on participation in activities including social play (Baranek et al., 2006; Baker et al., 2008; Tomcheck and Dunn, 2007; Ben-Sasson et al., 2009). To date however, research has primarily been examining participation in structured after-school leisure activities. Few studies have focused specifically on researching outdoor free-play with children with disabilities. Yet we know that from a child's perspective, play is highly important and is a significant contributor to well-being (Coyne, Dempsey, Comiskey and O'Donnell, 2012).

Since 2014, a research programme has been developed in the Department of Occupational Science and Occupational Therapy, University College Cork, to begin to explore play needs of children in Ireland from a rights-based approach to social inclusion. Five exemplars are briefly outlined below, to determine the state of play evidence and identify a way forward. Through establishing this programme of research, it is hoped that the goal of addressing discrimination and social exclusion through consideration of the physical characteristics of play environments can be addressed.

Project One: Scoping review of playground environments

The aim of this study was to establish what is known about accessibility and usability of public playgrounds, guided by the UNCRC, which establishes the rights for children to have accessible and inclusive environments available to them. Accessibility is enabled when the child's functional capacity is matched well with the demands of the physical environment. In contrast, usability refers to the capacity for all people to equally access and use the environment (Iwarsson and Stahl, 2003). Fourteen studies were identified that had examined playground usability and accessibility for children under twelve years of age. Synthesis of evidence suggested that playgrounds are frequently inaccessible and unusable for many children, with few guidelines on designing for

social inclusion; no studies were identified that have researched design, usability, or social inclusion in playgrounds in Ireland (Moore and Lynch, 2015).

Project Two: Heritage Council review of children's connection with the outdoors

The Heritage Council commissioned this project to report on the connection between children and the outdoors in contemporary Ireland. From the desk-based and qualitative data with 123 children, the report identified that children experience the outdoors primarily through play. However, there is a lack of policy in Ireland that supports children's engagement with the outdoors. Furthermore, there is a lack of data on children's lives to guide policy in relation to play needs and play preferences (Kilkelly et al., 2015; Moore, 2015).

Project Three: Usability and accessibility of Fitzgerald's Park, Cork

This project was undertaken to explore the question: "Do Universal Design guidelines translate to usability? The qualitative study explored the experiences of nine children with special needs, aged nine to sixteen years, in using the new universally designed playground in Cork city centre. Universal Design is the "design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability" (National Disability Authority, 2016). Similar to other studies, findings identified that parts of the playground were unusable for some individuals due to individual differences in play styles combined with the flow and design of the playspace (Prellwitz and Skar, 2007; Ripat and Becker, 2012). There is a lack of data on play preferences of children with different disabilities, which needs to be considered in future playground research (Barron et al., 2016). This lack of knowledge, in addition to the lack of clear guidelines on designing usable and accessible playgrounds (Moore and Lynch, 2015), contributes to the ongoing challenges in providing equitable play opportunities for children in public playgrounds in Ireland.

Project Four: Whole school approach: an inclusive approach to designing for play in the school-yard

In this study, a whole-school approach was employed to research with children in a local primary school about their play preferences for outdoor play to inform the redesign of the playground. The study was guided by a rights-based approach to children having a say in play provision (UNCRC General Comment 17). All children contributed to the study, with eighteen taking part in six focus groups to support data analysis and synthesis. The outcome was a report to the school to guide the provision of a new playspace, which was subsequently built and officially opened, June 2016 (see <http://www.gaelscoiluiriada.ie/nuachtnews/cul-anti-oscaill-oifigiuil/?lang=en>). One finding from this study was that there is a need for Irish guidelines on good practice, in designing for play with children (see examples from other countries: UK: Dunn, Moore and Murray, 2003; Australia: National Heart Foundation, 2013). This was established as one of the objectives of the Irish Play Policy, yet to date no progress has been made on this issue.

Project Five: Ludi COST Project: Play for Children with Disabilities (2014-2017):

Ludi is a European COST initiative, aimed to establish a network of researchers who are experts on play for children with disabilities. The need for the Ludi forum came about as play is as yet an underexplored and fragmented area of study, and consists of disparate fields including landscape architecture, education, rehabilitation, occupational science, and robotics (see <http://ludi-network.eu/>). The first phase of the Ludi project involved a review of barriers to play for children with disabilities: significantly, across Europe, it was found that there are few guidelines on designing for play. Furthermore, children with disabilities are rarely represented in research on play needs, barriers, and preferences (Barron et al., 2016).

Conclusion

To summarise, these studies show that although the Irish Play Policy identified the importance of child-centred, inclusive, equitable play provision for children, little progress has been made to date to progress this agenda. There are no national guidelines for designing for play, for including children and communities in designing for play, and a continued lack of evidence from Irish play research. The Play Policy hoped to progress play research through use of the longitudinal study: Growing Up in Ireland. Yet to date, there is little evidence of data being extrapolated on play itself, separate to sport, exercise, and leisure. For example, Better Outcomes Brighter Futures (2014) and the National Physical Activity Plan for Ireland (Department of Health, 2016), both use data on sport and exercise to inform policy. Indeed, the NPAP recommends physical activity in early childhood as an action. However, play is not the same as leisure, sport, or exercise but in older children is often seen as interchangeable (Lynch and Moore, 2016). While exercise is important as an action for children, it communicates an adultist perspective on health and fitness, rather than focusing on the natural form of activity that young children engage in, i.e. play occupation. From a rights-based approach, the centrality of play in early childhood needs to be acknowledged to support evidence-informed policy developments particularly considering the current Play Policy review and the pending Early Years Strategy.

Finally, there is a significant need to focus research on the experiences and play preferences and needs of children with disabilities in Ireland. Furthermore, there is a need to concurrently research whole outdoor play environments (not just built or public) to identify how to reduce barriers to participation for these children. Although the Irish Play Policy established these as important issues of concern in 2004, without governmental support and investment, few actions were implemented. However, since 2004, the international

community rallied to produce the General Comment 17 (United Nations Committee on the Rights of the Child, 2013) that urges states to take play seriously, followed by the Internal Play Associations position statement on the play rights of disabled children (2015). There is an international awareness of the importance of play, and the threat of play deprivation: perhaps this time things will be different for Ireland's play agenda.

Author information

Helen Lynch is an Occupational Therapist who worked for 20 years with families and children with special needs before joining the department of Occupational Therapy in UCC as full-time lecturer in 2004. She completed a master's degree researching time-use (occupation and environments) of children in middle-childhood (2007). In 2012, she completed a PhD in Social Sciences exploring physical play and home learning environments of infants under two. Helen's research interests are in occupational science in relation to child well-being, environments and play. She is an Irish representative for a European COST Project on Play for Children with Disabilities, Ludi: <http://ludi-network.eu/>

References

- Anaby, D., Hand, C., Bradley, L., Direzze, B., Forhan, M., Digiaco, A., and Law, M. (2013) *The Effect of the Environment on Participation of Children and Youth with Disabilities: a Scoping Review*, Disability and Rehabilitation, 1-10.
- Baker, A. E., Lane, A., Angley, M. T., and Young, R. L. (2008) *The Relationship Between Sensory Processing Patterns and Behavioral Responsiveness in Autistic Disorder: A Pilot Study*, *Journal of Autism and Developmental Disorders*, Vol. 38 (5), pp. 867-875.
- Baranek, G., David, F., Poe, M., Stone, W., and Watson, L. (2006) *Sensory Experiences Questionnaire: Discriminating Sensory Features in Young Children with Autism, Developmental Delays and Typical Development*, *Journal of Child Psychology and Psychiatry*, Vol. 47, pp. 591-601.
- Barron, C., Beckett, A., Coussens, M., Desoete, A., Cannon-Jones, N., Lynch, H., Prellwitz, M., and Fenney Salkeld, D. (2016) *Barriers to Play and Recreation for Children and Young People with Disabilities: Exploring Environmental Factors*. Berlin: DeGruyters. Available online at <https://www.degruyter.com/view/product/481918>
- Ben-Sasson, A., Hen, L., Fluss, R., Cermak, S., Engel-Yeger, B., Gal, E. (2009) *A Meta-Analysis of Sensory Modulation Symptoms in Individuals with Autism Spectrum Disorders*, *Journal of Autism and Developmental Disorders*, Vol. 39, pp. 1-11.
- Beunderman, J. (2010) *People Make Play: The Impact of Staffed Play Provision on Children, Families and Communities*. London: National Children's Bureau.
- Burdette, H. L. and Whitaker, R. C. (2005) *Resurrecting Free Play in Young Children: Looking Beyond Fitness and Fatness to Attention, Affiliation and Affect*. *Archives Paediatrics Adolescent Medicine*, Vol. 159, pp. 46-50.
- Committee on the Rights of the Child (CRC), General Comment No.17 (2013) on the Right of the Child to Rest, Leisure, Play, Recreational Activities, Cultural Life and the Arts (Art.31), Geneva: United Nations.
- Coyne, I., Dempsey, O., Comiskey, C., and O'Donnell (2012) *Life as a Child and Young Person in Ireland: Report of a National Consultation*, Dublin: Department of Children and Youth Affairs.
- Department of Children and Youth Affairs (2014) *Better Outcomes, Brighter Futures The National Policy Framework for Children and Young People 2014-2020*, Dublin: National Stationery office.

Department of Health (2016). *Get Ireland Active: The National Physical Activity Plan for Ireland*. Dublin: Healthy Ireland.

Dunn, K., Moore, M. and Murray, P. (2003). *Developing Accessible Play Space: a Good Practice Guide*. Office of the deputy Prime Minister, UK. Available online at

<http://www.thenbs.com/PublicationIndex/DocumentSummary.aspx?PubID=428&DocID=265752>

Fjortoft, I., and Sageie, J. (2000) *The Natural Environment as a Playground for Children; Landscape Description and Analyses of a Natural Playscape, Landscape and Urban Planning*, Vol. 48, pp. 83-97.

Gill, T. (2014) *The Benefits of Children's Engagement with Nature: A Systematic Literature Review, Children, Youth and Environments*, Vol. 24, pp. 10-34.

International Play Association (2015). *The Play Rights of Disabled Children: Position Statement*. Available online at

<http://ipaworld.org/wp-content/uploads/2015/08/IPA-Disabled-Children-Position-Stmt.pdf>

Iwarsson, S., Stahl, A. (2003) *Accessibility, Usability and Universal Design Positioning and Definition of Concepts Describing Person-Environment Relationships, Disability and Rehabilitation*, Vol. 25 (2), pp. 57-66.

Kilkelly, U., Lynch, H., O'Connell, A., Moore, A., Falcini, U., and Field, S. (2015) *Children and the Outdoors: Contact with the Outdoors and Natural Heritage among Children Aged 5 to 12: Current Trends, Benefits, Barriers and Research Requirements*, Irish Heritage Council.

King, G., McDougall, J., DeWit, D., Petrenchik, T., Hurley, P., and Law, M. (2009) *Predictors of Change Over Time in the Activity Participation of Children and Youth with Physical Disabilities, Children's Health Care*, Vol. 38,(4), pp. 321-351.

Kolehmainen, N., Francis, J., Ramsey, C., Owen, C., McKee, L., Ketelaar, M., and Rosenbaum, P. (2011) *Participation in Physical Play and Leisure: Developing a Theory-and Evidence-Based Intervention for Children with Motor Impairments*, BMC Paediatrics, Vol. 11, pp. 1-8.

Korpela, K., Ylen, M., Tyrvaainen, L., and Silvennoinen, H. (2008) *Determinants of Restorative Experiences in Everyday Favourite Places, Health & Place*, Vol. 14, pp. 636-652.

Kuo, F., Faber, T. (2004) *A Potential Natural Treatment for Attention-Deficit Hyperactivity Disorder: Evidence from a National Study*, American Journal of Public Health, Vol. 94, pp. 1580-1586.

Law, M., Finkelman, S., Hurley, P., Rosenbaum, P., King, S., King, G. and Hanna, S. (2004) *Participation of Children with Physical Disabilities: Relationships with Diagnosis, Physical Function, and Demographic Variables*, Scandinavian Journal of Occupational Therapy, Vol. 11, pp. 156-162.

Lynch, H. and Moore, A. (2016) *Play as an Occupation in Occupational Therapy, British Journal of Occupational Therapy*, Vol. 79 (9), pp. 519-520.

Moore, A. (2015). *To Explore and Understand Children's Conceptualisations of Play and Well-Being in Contemporary Ireland*. Unpublished Master's Thesis, University College Cork.

Moore, A. and Lynch, H. (2015) *Accessibility and Usability of Playground Environments for Children under 12: a Scoping Review, Scandinavian Journal of Occupational Therapy*, Vol. 22(5), pp. 331-344.

National Children's Office (2004) *Ready, Steady Play! A National Play Policy*, Dublin: The Stationary Office.

National Disability Authority (2016) *What is Universal Design*. Available online at <http://universaldesign.ie/What-is-Universal-Design/> Accessed January 2017.

- National Heart Foundation of Australia (Victoria) (2013). *Space for Active Play, Developing Child-Inspired Play Space for Older Children*. Melbourne: National Heart Foundation of Australia.
- Poulsen, A., Ziviani, J., Cuskelly, M. (2007) *Perceived Freedom in Leisure and Physical Co-Ordination Ability: Impact on Out-Of-School Activity Participation and Life Satisfaction, Child Care, Health and Development*, Vol 33, pp. 432–40.
- Prellwitz, M. (2007) *Playground Accessibility and Usability for Children with Disabilities*. PhD thesis: Lulea University of Technology, Sweden.
- Prellwitz, M. & Skar, L. (2007). *Usability of Playgrounds for Children with Different Abilities. Occupational Therapy International*, 14(3), 144–155
- Ripat, J., & Becker, P. (2012). Playground Usability: What do Playground Users Say? *Occupational Therapy International*, 19, 144-153
- Sallis, J., Prochaska, J., Taylor, W. (2000) *A Review of Correlates of Physical Activity of Children and Adolescents. Medicine & Science in Sports & Exercise*, Vol. 32, pp. 963-975.
- Taylor, A. F., Kuo, F. E., Sullivan, W.C. (2001) *Coping with ADD: The Surprising Connection to Green Play Settings. Environment and Behaviour*, Vol. 33 (1), pp. 54-77.
- Tomcheck, S., Dunn, W. (2007) *Sensory Processing in Children With and Without Autism: A Comparative Study Using the Short Sensory Profile. American Journal of Occupational Therapy*, Vol. 61 (2), pp. 190-200.
- Ulrich, R., Simons, R., Losito, B., Fioriteo, E., Miles, M., Zelson, M. (1991) *Stress Recovery During Exposure to Natural and Urban Environments, Journal of Environmental Psychology*, Vol. 11, pp. 201-230.
- United Nations Convention on the Rights of the Child (UNCRC). (1989) *Convention on the Rights of the Child*, Geneva: United Nations.
- United Nations Committee on the Rights of the Child. (2013). General comment No. 17 on the Right of the Child to Rest, Leisure, Play, Recreational Activities, Cultural Life and the Arts (art. 31), Geneva: United Nations.
- Webb, R. (2003) *Public Play Provision for Children with Disabilities*, Sugrath: National Disability Authority.
- Wells, N. M., Evans, G. W. (2003) *Nearby Nature: A Buffer of Life Stress Among Rural Children, Environment and Behavior*, Vol. 35, pp. 311-330.



Bouncing back: Blending interventions to support young adults with autism transition into adulthood

Sheila Cross, Rachel Ferguson and Fiona McCaffrey

Background

Resilience can be defined as positive and beneficial outcomes which result from successfully handling stressful events (Masten, Best, and Garmezy, 1990). Building resilience and developing resilience-promoting interventions therefore involves targeting “protective and vulnerability forces at multiple levels of influence — culture, community, family and the individual” (Cicchetti, 2010, p.151). In considering individuals with autism spectrum disorder (ASD) who experience a spectrum of lifelong challenges (Howlin, 2013) with social interaction, communication and restricted or repetitive interests and behaviours (DSM; 5, APA, 2013) acquiring resilience skills is vitally important.

The difficulties experienced by individuals with ASD can negatively impact their ability to engage in activities of daily life (Koenig and Rudney, 2010), conduct typical relationships (Test, Smith and Carter, 2014) and develop functional life skills (Carter, Common, Sreckovic, Huber, Bottema-Beutel, Gustafson, et al., 2013; Wagner, Newman, Cameto, Levine, and Garza, 2006) which can inhibit the achievement of typical developmental and socio-emotional milestones as they approach adulthood.

Upon approaching adulthood, research indicates that adolescents with autism are more likely to experience lower rates of paid employment (Taylor and Seltzer, 2011); independent living (Farley McMahon, Fombonne, Jenson, Miller, Gardner et al 2009); academic achievement (Shattuck, Narendorf, Cooper, Sterzing, Wagner, and Taylor 2012) and friendships (Newman Wagner, Knokey, Marder, Nagle, Shaver et al 2011) compared to their typically developing peers. This suggests that adolescents with ASD are unprepared and inadequately equipped with essential skills for transitioning to adulthood.

Supporting young people's resilience involves identifying their individual strengths, developing coping skills, acquiring a positive attitude, developing problem solving skills, and

regulating emotions. These are skills which young people with ASD may often struggle with. Blending a range of strategies can prove beneficial in providing social support to young people with ASD as they progress into adulthood.

Objectives

This article describes a transdisciplinary approach (King, Strachan, Tucker, Duwyn, Desserud, and Shillington (2009)) which involved blending key psychosocial interventions to support and develop resilience skills to aid the transition of three adolescents into adulthood. These adolescents were referred to Middletown Centre for Autism (MCA). The transdisciplinary approach involves one member of the transdisciplinary team acting as the link with the family, school and community. This promotes collaborative working among team members with the aim of delivering a holistic intervention to the young person with ASD and a programme of support to the family, as well as to educational and health professionals working with the young person with ASD.

Method

Design

A multiple case study design was employed.

Ethics

Informed consent was sought from the school, the parent and where appropriate the adolescent in accordance with Middletown Centre for Autism (MCA) research procedures.

Participants

Three males aged fourteen to eighteen years (James, Tim and Caolan) were referred to MCA. The three adolescents, their parents and the professionals working with the three adolescents in school/community setting consented to take part in the study. All information pertaining to the participants has been anonymised to protect their identity.

James attended a Special Needs School until the age of sixteen, when he was removed following a

succession of aggressive incidents. Main areas of difficulty included communication, emotional regulation, self-help skills, interaction with peers, staying focused on task and sensory needs.

Tim had a diagnosis of Asperger syndrome and Attention Deficit Hyperactivity Disorder (ADHD), he attended a mainstream school but had been experiencing significant difficulty in relation to social skills, homework and bullying in his educational placement, having previously been removed from a mainstream school.

Caolan also attended a mainstream school and had a diagnosis of Asperger's, ADHD and Oppositional Defiant Disorder. Caolan had changed schools several times because of difficulties relating to behaviour, aggression, absconding and disruption of school and class activities, organisational skills and sleep.

All the adolescents referred required resilience support to help them transition successfully into further education or adulthood.

Transdisciplinary intervention programme

In the transdisciplinary model, any member of the specialist team can act as the lead professional delivering an individualised Learning Support Plan. The lead professional draws on the experience of the specialist team, which consists of: teachers, speech and language therapists, autism intervention officers and occupational therapists. Employing the transdisciplinary model also allows for skills to be transferred between all team members, extending their traditional roles.

Utilising a transdisciplinary model, for each of the adolescents, the team worked in a co-ordinated way, for three school terms, with the adolescent, their parents and other educational and health professionals to assess and address identified needs across the home, school and community settings.

This allowed for the development of a holistic intervention to support the adolescent in addition to creating a programme of support to the family

and to educational and health professionals working in the school setting (See Table 1).

Outcome measures

The transdisciplinary model commences with a period of formal and informal assessment with the individual with ASD, their caregiver and relevant professionals working with the young person within the school and community. In collaboration with caregivers and teachers, the Intervention Coordinator creates an individualised child-centred set of goals and a tailored intervention programme to facilitate achievement of each goal.

Once intervention commences, the Intervention Co-ordinator liaises regularly with all relevant parties, across settings, to review and monitor progress.

Six months following intervention, semi-structured interviews are conducted with caregivers and the young person with autism. This gives participants the opportunity to voice their views on the effectiveness of the intervention and the impact it had on them. Education and health professionals involved in supporting each adolescent with ASD also completed a self-report questionnaire evaluating the effectiveness of the intervention strategies, support and advice delivered by the MCA.

Results

This section first reports on the results of the intervention and then of the follow up at six months.

James

MCA staff reported that James had successfully attended an IT course at a College for Further Education and was volunteering at a local garage every week for 50 minutes.

His mother reported that James is now secure in spending time away from her and he walks to work without support. His behaviour is more manageable. Any anxiety related to his speech volume had improved over the last 18 months.

Area of Difficulty	Strategy Employed	Supports
<p><i>Anxiety</i></p> <p>Anxiety is often related to difficulties with communication, predicting outcomes, understanding social interactions and sensory processing. Self-reported maternal health</p>	<p><i>Anxiety Management</i></p> <p>Identifying the triggers that cause anxiety and providing strategies that aim to reduce the confusion and increase a sense of calm and control.</p>	<p>Environmental supports e.g. providing a structured environment with clear boundaries.</p> <p>Using visual e.g. timetables and symbols to recognise and communicate emotions.</p> <p>Incorporating sensory breaks and using relaxation techniques.</p>
<p><i>Communication and understanding what behaviour / reaction is expected.</i></p>	<p><i>Visual Strategies</i></p> <p>Supporting communication and help manage anxiety.</p>	<p>Visual Strategies- including body movements, environmental cues, pictures, objects, written language and voice output devices.</p>
<p><i>Emotional Regulation</i></p> <p>Difficulties with emotion regulation or dysregulation, may lead to an increased risk for disruptive behaviour, poor interpersonal relations and difficulties with academic achievement.</p>	<p><i>Emotional Regulation Strategies</i></p> <p>For successful maturation and development of independence skills it is advisable to teach effective age and context appropriate coping strategies to a young person with autism from an early age.</p>	<p>Strategies included: Social behaviour mapping to gain a long term view of individuals actions, breathing exercises, meditation techniques, teaching recognition of feelings and what to do when feeling this way (using visuals, 5 point scale, feeling thermometer, social stories etc.), practice how to deal with emotions when calm, arrange calm area with school and discuss appropriate usage (i.e. it is not a reward or punishment), discuss anxiety provoking situations and assist the individual with ASD to recognise appropriate reactions and coping strategies.</p>
<p><i>Homework</i></p> <p>Difficulties with organisational skills and working memory can impact on an individual's ability to complete tasks.</p>	<p><i>Homework Strategies</i></p> <p>To ensure successful completion of tasks such as homework it is important to teach the individual why/ purpose of completing a task so they can try and understand the relevance and need to complete it.</p>	<p>Homework to be noted in homework diary, Prompt to examine timetable to determine when homework's are due, reminders on smart phone, staff trained and encouraged to be mindful of their responses / praise, to provide sensory stimulation to help with attention/focus</p>

Table 1: Examples of some strategies and supports used to develop resilience skills.

Caolan

Caolan reported he was more self-aware and was more flexible in his interactions with others. He also reported that when he was feeling anxious, he was now able to independently ask for assistance. His parents also noted that he had a better ability to cope in social situations. They reported that Caolan's confidence has improved greatly stating, "I think he feels that people have a better understanding of him now and he has learned to take other people's points of view into consideration".

Tim

Tim acknowledged that his homework completion had improved but it was still an ongoing issue. Education staff reported that despite this, the most useful part of the intervention was the Intervention Co-ordinator and transdisciplinary model. Staff reported that this enabled a set of disparate inputs from the key players, to be orchestrated and coordinated, on an ongoing basis towards supporting Tim, collaboratively.

Six month follow-up

James

James reported that he liked his job in the local shop, he could get dressed independently, make a sandwich and liked to go out by himself and pay for items himself in a shop. His mother also reported that he had made improvements in his ability to attend to task, in his self-help skills and behaviour. His mother reported that she still felt about her son but was very proud of his achievements.

Caolan

Caolan stated "I calm down more easily now. I don't need to have to calm down as much now, as I understand people a bit more now". School staff also reported a good improvement; the experience of working with MCA had changed lives for the better. Caolan's parents also stated that "Caolan was out of control [and] the help he received from MCA got him back on track. He was frustrated with other people, he wasn't good at tolerating others".

Tim

Tim reported feeling calmer at school. He reported that he felt he could control his behaviour better in more situations. Tim's parent reported that although homework was still an issue, his reflection on his behaviour had improved, "he thinks about the consequences of his behaviour now, he is more aware of people's opinions".

Conclusions

This study emphasises the successful implication of utilising a transdisciplinary approach to support adolescents with ASD. Employing individually tailored intervention programmes can improve and develop resilience skills to facilitate the achievement of age appropriate 'social norms' such as attending school, forging friendships with peers, contributing to the community, gaining employment and undertaking more responsibilities at home. These case studies illustrate that working to the strengths, interests and needs of the young person with ASD, can successfully help them to bounce back from difficult periods in their life and make a successful transition into adulthood.

Author information

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References

- American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Carter, E. W., Common, E. A., Sreckovic, M. A., Huber, H. B., Bottema-Beutel, K., Gustafson, J. R., Dykstra, J and Hume, K. (2013) *Promoting Social Competence and Peer Relationships for Adolescents with Autism Spectrum Disorders*. Remedial and Special Education. Vol.35 (2), pp.91-101. Available online at:<http://rse.sagepub.com/content/early/2013/12/23/0741932513514618>
- Cicchetti, D. (2010) Resilience under Conditions of Extreme Stress: A Multilevel Perspective. *World Psychiatry*, Vol.9, pp. 145-154.
- Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., Block, H., Pingree, C.B. Ritvo, E.R., Ritvo, R.A. and Coon, H. (2009) *Twenty year Outcome for Individuals with Autism and Average or Near average Cognitive Abilities*. *Autism Research*, Vol. 2(2), pp. 109-118.
- Howlin, P. (2013) *70 Years of Research on Autism — How Far have we Come?* Link, Autism Europe, Vol. Dec 60, pp. 4 – 6.
- King, G., Strachan, D., Tucker, M., Duwyn, B., Desserud, S. and Shillington, M., (2009) *The application of a transdisciplinary model for early intervention services. Infants and Young Children*, Vol.22(3), pp.211-223.
- Koenig, K. P., and Rudney, S. G. (2010) *Performance Challenges for Children and Adolescents with difficulty Processing and Integrating Sensory Information: A Systematic Review*. *The American Journal of Occupational Therapy*, Vol. 64(3), pp. 430-442.
- Masten, A.S., Best, K and Garmezy, N. (1990) *Resilience and Development: Contributions from the Study of Children who overcome Adversity*. *Development and Psychopathology*, Vol. 2, pp. 425-444.
- Newman, L., Wagner, M., Knokey, A., Marder, C., Nagle, K., Shaver, D. Wei, X., Cameto, R., Contreras, E., Ferguson, K., Greene, S., Schwarting, M. (2011) *The post-high school outcomes of young adults with disabilities up to 8 years after high school*. A report from the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2011-3005) Menlo Park, CA: SRI International. Available online at: <https://ies.ed.gov/ncser/pubs/20113005/pdf/20113005.pdf>

Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., and Taylor, J. L. (2012) *Postsecondary Education and Employment among Youth with an Autism Spectrum Disorder*. Paediatrics, 129, pp.1042-1049. Available online at: <http://pediatrics.aappublications.org/content/early/2012/05/09/peds.2011-2864.full.pdf+html>

Taylor, J. L., and Seltzer, M. M. (2011) *Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood*. Journal of Autism and Developmental Disorders, Vol. 41(5), pp. 566-574.

Test, D., Smith, L. and Carter, E. (2014) *Equipping Youth with Autism Spectrum Disorders for Adulthood: Promoting Rigor, Relevance and Relationships*. Remedial and Special Education, Vol.35(2), pp.80-90. Available online from: <http://rse.sagepub.com/content/early/2014/01/01/0741932513514857.full.pdf+html>

Wagner, M., Newman, L., Cameto, R., Levine, P., and Garza, N. (2006) *An Overview of Findings from Wave Two of the National Longitudinal Transition Study-2 (NLTS2)* (NCSE 2006-3004). Menlo Park, CA: SRI International.

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Before You Begin

Exploring the education needs of families of transgender young people in the Republic of Ireland: Overview of a PhD study

Danika Sharek

Introduction

Transgender young people may face a number of challenges to their well-being, including depression, self-harm and suicide; physical health issues; alcohol and substance misuse; higher incidence of violence, harassment, and discrimination; and challenges in social relations with family and friends (Higgins et al., 2016; McNeil, Bailey, Ellis, Regan, and Transgender Equality Network Ireland (TENI), 2013). Research shows that a family's behaviours towards a transgender family member, whether affirming or rejecting, can seriously impact on a transgender young person's mental health and resilience (Ryan, Russell, Huebner, Diaz, and Sanchez, 2010). Within Ireland, transgender young people themselves have identified the importance of family support for their own well-being (Dunne and Turraoin, 2016). Although the importance of family support is essential for the well-being of transgender young people, many transgender people within Ireland report being rejected or not supported by their family (Dunne and Turraoin, 2016; McNeil et al., 2013). Within the literature, education and information have been identified as playing an important role in a family's ability to accept and support a transgender family member (Dunne and Turraoin, 2016; Riley, Sitharthan, Clemson, and Diamond, 2011). While there is a growing body of literature on the importance of education and information for families of transgender people, there have been no studies exploring the education needs of these families in an Irish context.

Aims and objectives

This PhD study aims to explore the education needs of families of transgender young people in the Republic of Ireland and how best to address these needs. The objectives are:

- 1 to identify the education needs of family members of transgender young people in the Republic of Ireland;
- 2 to design, develop, and evaluate an education programme for these families which takes into account their identified needs; and
- 3 to make recommendations for developing the programme, future research, policy and practice.

Methodology

This study is informed by Community-Based Participation Research (CBPR) and a Family Life Education (FLE) framework. CBPR is defined as "an alternative research paradigm" which, "... focuses on relationships between academic and community partners, with principles of co-learning, mutual benefit, and long-term commitment" (Wallerstein and Duran, 2006:312). CBPR values the strengths, knowledge, and skills of both community partners and the academic-researcher, suggesting the importance of building partnerships to develop and conduct a needs-based and relevant research study (Minkler and Wallerstein, 2003). Family Life Education (FLE) is a strengths-based approach to family education, using a preventative framework to promote positive well-being and healthy family functioning (National Council on Family Relations (NCFR), 2016). In addition, the study is guided by the gender affirmative theory and model, which asserts that gender may be fluid and diverse, that its development is complex, and that this is a natural, not pathological, phenomenon (Hidalgo et al., 2013). Within this approach, there is no need to attempt to change or 'treat' a gender diverse child or young person, as there is nothing viewed as inherently requiring alteration as regards their gender identity (Hidalgo et al., 2013). The voice of the child is central, with the child presumed to be capable, free and able to understand and assert their identity (Hidalgo et al., 2013). The underlying basis for this approach is the belief that by affirming and supporting their transgender family member, families and parents can promote healthy adjustment (Hidalgo et al., 2013).

This mixed methods study has three primary phases: Consultation; Design and Development; and Evaluation. This article will focus on findings related to the Consultation phase, which aimed to conduct a needs analysis with key stakeholders in order to identify their education needs. The first sub-phase included seven in-depth, semi-structured interviews with family members of transgender young people and professionals working in organisations that support transgender young people and their families. The next sub-phase of the consultation included surveys with two cohorts: 1. family members (n=18) and 2. transgender young people (n=14). The aim of these surveys was to identify key areas of questions/concerns for the cohorts. The family survey asked family members about questions/concerns they had regarding their transgender family member, whereas the transgender young people's survey asked them about questions/concerns they had relating to their family.

Ethical approval to conduct this study was received from the researcher's university. The lower age limit for youth participation in the anonymous survey was 14 years and return of the survey implied consent to participate. No parent/guardian consent was sought. Strategies to off-set the absence of parent/guardian consent included utilising young person-friendly protocols and consent procedures; partnering with experienced community youth agencies; and maximising attention towards confidentiality, anonymity, and voluntary participation (Flicker and Guta, 2008).

All data were analysed using the iterative, six step process for inductive, semantic, thematic data analysis developed by Braun and Clarke (Braun and Clarke, 2006). This is a data-driven process in which the data from participants drives the generation of themes, which explain the data and answer the research question.

Brief overview of consultation findings

Within the interviews, all of the participants alluded to the fact that families are often completely unaware and uninformed about what it means to be transgender. One mother succinctly phrased her confusion:

*Transgender, what the f*** is that like? You know? — Sinead, mother to a transgender female aged 16.*

This lack of knowledge can lead to families feeling confused and overwhelmed. One professional participant noted that:

Quite often, you know, the parents know absolutely nothing about the area, so it comes totally out of the blue. People are absolutely shell shocked. They don't know where to turn. They don't know where to go...They don't know what to do. — Professional 4

The issue of not having Irish-specific education resources was highlighted by all of the participants and there were no ongoing or sustainable education programmes available to families:

Like there would be, I think there is a definite lack of information in Ireland for parents and for young people — Professional 1

Within the survey, the family members identified 92 areas of questions/concerns in relation to having a transgender family member, with five primary themes emerging: health; emotional responses; social issues; general support and moving forward; and other issues. The most common questions/concerns were health-related issues, including both physical and mental health and how to access support:

What does this mean medically speaking? — Mother

Other family's questions/concerns were classed as emotionally-based responses and were defined by emotions such as fear and worry of finding out their family member was transgender:

"I felt heartbroken for my child and for myself" — Mother. There were also a number of questions/concerns around social issues, particularly as regards whether their family member would be accepted or discriminated against and how best 'come out' to other people:

How will he make friends? Is social life going to be a nightmare that kills us? — Father

Families also had questions/concerns about how to move forward in supporting their transgender family member and how to access support. There were a number of other concerns around areas including school, legal and administrative issues, and impact on siblings.

Within the young people's survey, the transgender young people provided 44 individual responses, with eight separate themes emerging: understanding; acceptance, respect, and perception; doubt, belief, or 'it's just a phase'; emotional responses; support; negative behaviour; coming out to others; and language/pronouns. The majority of their questions/concerns were around whether their family members would understand who they are — both literally in the sense of what it means to be transgender and more figuratively in the sense that being transgender is an innate part of their being.

Will my family understand what it means to be transgender? — Male, 18 years old

In addition, there were a number of questions/concerns around how participants' family members would perceive them upon realising they were transgender, and whether their family would be able to accept them for who they are:

I was worried I wouldn't be accepted — Female, 18 years old.

Several participants were concerned that their family would not believe they were transgender or think 'it's just a phase'. Nearly fifteen per cent expressed explicitly that they were 'afraid' or 'worried' about their family's reaction. Others had questions/concerns over whether they would receive support from their family, while some feared being at the receiving end of negative behaviours such as being kicked out of the house. Smaller percentages had questions/concerns over coming out to others and around whether their family would use the appropriate language when speaking with them.

In summary, the findings from the consultation underscored the need for the development of an education programme for families and identified key areas for consideration in its development. It was of critical importance to ensure that families' and young people's areas of questions/concerns were included within the education programme. With this in mind, the education programme content was reviewed and modified to reflect these findings from the consultation phase. For example, as health was such a prominent concern for families, the health module content was reviewed and modified to ensure that it addressed clearly both the physical and mental health needs of transgender young people and how to access healthcare supports. As emotional responses appeared to be so significant to families, the content was reviewed to ensure that each module addressed not only the factual or information elements of the topic, but also explicitly addressed the emotional elements. Where appropriate, additional emotionally-based text and videos were added to the education programme. In terms of young people's concerns, the education programme content was modified to reflect more fully the questions/concerns of young people around coming out within the family. This was accomplished by including written text about their questions/concerns, as well as personal stories from transgender young people about their experiences of coming out within a family context. A similar process of reviewing and modifying the module content, as well as the

overall education programme, was conducted to reflect these findings.

The study is currently in the development sub-phase. Once the education programme is developed, the researcher will conduct a mixed methods evaluation of the programme to explore participants' experiences with the education programme and to evaluate its impact.

Discussion and conclusion

This PhD research aims to explore the education needs of families of transgender young people and to address these needs by designing, developing, and evaluating a gender-affirmative education programme for these families. The findings of the study to date reflect much of the literature, indicating that education plays an important role in families' ability to accept and support a transgender family member (Gray, Sweeney, Randazzo, and Levitt, 2015; Kusalanka, Weiner, and Mahan, 2014; Meadow 2011; Norwood 2013; Pearlman 2006; Rahilly 2015; Riley et al., 2011; Riley, Sitharthan, Clemson, and Diamon, 2013; Wren, 2002). However, the study findings have also shown a lack of educational opportunities for families of transgender young people in the Republic of Ireland, as well as identified a number of areas of educational importance for families and transgender young people. It is hoped that this education programme can help families by providing an innovative, needs-based resource for information and education, which in turn, may foster enhanced resilience for transgender young people.

Author information

Danika Sharek is a PhD candidate in Trinity College Dublin School of Nursing & Midwifery, funded by the Irish Research Council, and under the supervision of Dr Edward McCann and Sylvia Huntley-Moore. Danika's PhD research aims to explore the education needs of families of transgender young people in the Republic of Ireland and how best to address these needs. Danika holds an MSc in Applied Social Research

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References

- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), pp. 77-101.
- Dunne, P. and Turraoin, C. (2016) *National Trans Youth Forum Report*. Dublin, Ireland: Trinity College Dublin Equality Fund, Transgender Equality Network Ireland (TENI), BeLonG To Youth Services, the Irish Transgender Student Alliance (ITSA), and ILGA-Europe.
- Flicker, S. and Guta, A. (2008) Ethical approaches to adolescent participation in sexual health research. *Journal of Adolescent Health*, 42(1), pp. 3-10.
- Gray, S. A. O., Sweeney, K. K., Randazzo, R. and Levitt, H. M. (2015) "Am I doing the right thing?": Pathways to parenting a gender variant child. *Family Process*, 55(1), pp. 1-16.
- Hidalgo, M. A., Ehrensaft, D., Tishelman, A. C., Clark, L. F., Garofalo, R., Rosenthal, S. M., Spack, N. P. and Olson, J. (2013) The Gender Affirmative Model: What we know and what we aim to learn. *Human Development*, 56(5), pp. 285-290.
- Higgins, A., Downes, C., Murphy, R., Sharek, D., de Vries, J., Begley, T., McCann, E., Sheerin, F. and Smyth, S. (2016) *The LGBTIreland Report: The National Study of the Mental Health and Wellbeing of Lesbian, Gay, Bisexual, Transgender and Intersex People in Ireland*. Dublin, Ireland: Gay and Lesbian Equality Network (GLEN) and BeLonG To Youth Services.
- Kusalanka, K. A., Weiner, J. L. and Mahan, D. (2014) Child, family, and community transformations: Findings from interviews with mothers of transgender girls. *Journal of GLBT Family Studies*, 10(4), pp. 354-379.

McNeil, J., Bailey, L., Ellis, S., Regan, M. and Transgender Equality Network Ireland (TENI) (2013) *Speaking from the margins: Trans mental health and wellbeing in Ireland*. Dublin, Ireland: Transgender Equality Network Ireland (TENI).

Meadow, T. (2011) 'Deep down where the music plays': How parents account for childhood gender variance. *Sexualities*, 14(6), pp. 725-747.

Minkler, M. and Wallerstein, N., eds. (2003) *Community-Based Participatory Research for health*, San Francisco, CA, USA: John Wiley & Sons, Inc.

National Council on Family Relations (NCFR) (2016) *What is Family Life Education?*, Available: <https://www.ncfr.org/cfle-certification/what-family-life-education>.

Norwood, K. (2013) Meaning matters: Framing trans identity in the context of family relationships. *Journal of GLBT Family Studies*, 9(2), pp. 152-178.

Pearlman, S. F. (2006) Terms of connection: Mother-talk about female-to-male transgender children. *Journal of GLBT Family Studies*, 2(3-4), pp. 93-122.

Rahilly, E. P. (2015) The gender binary meets the gender-variant child: Parents' negotiations with

childhood gender variance. *Gender & Society*, 29(3), pp. 338-361.

Riley, E. A., Sitharthan, G., Clemson, L. and Diamond, M. (2011) The needs of gender-variant children and their parents: A parent survey. *International Journal of Sexual Health*, 23(3), pp. 181-195.

Riley, E. A., Sitharthan, G., Clemson, L. and Diamond, M. (2013) Recognising the needs of gender-variant children and their parents. *Sex Education*, 13(6), pp. 644-659.

Ryan, C., Russell, S. T., Huebner, D., Diaz, R. and Sanchez, J. (2010) Family acceptance in adolescence and the health of LGBT young adults. *Journal of Child and Adolescent Psychiatric Nursing*, 23(4), pp. 205-213.

Wallerstein, N. and Duran, B. (2006) Using Community-Based Participatory Research to address health disparities. *Health Promotion Practice*, 7(3), pp. 312-323.

Wren, B. (2002) 'I can accept my child is transsexual but if I ever see him in a dress I'll hit him': Dilemmas in parenting a transgendered adolescent. *Clinical Child Psychology and Psychiatry*, 7(3), pp. 377-397.

Resilience factors amongst higher education students with a care background

Seana Friel

Introduction

Going to university has become the common expectation for many young people living with their own families, but for care experienced young people it can be regarded as an extraordinary achievement (Cameron, Connelly and Jackson, 2015). Recent statistics revealed that thirty one percent of care leavers left care without formal qualifications compared with two percent of general school leavers (NI Care Leavers Statistical Bulletin, 2013). This has been linked to pre-care experiences such as abuse or neglect, missed schooling, low socio-economic status, low expectations from teachers and social workers, multiple placements and school changes; school truancy; and a lack of educational encouragement from carers (Berridge, 2007, 2012; Cashmore et al., 2007; Jackson et al., 2005; Jackson, 2006; Welbourn and Leeson, 2012).

Given the known multiple vulnerabilities of this population and their risk of poor educational outcomes, it is not surprising that the research focus is often on matters pertaining to their deficit, with quite a number of studies focusing on the low educational achievement of children in care (Darmody et al., 2013; Berridge, 2007). Substantially less is known about the factors contributing to the resilience and high academic achievement of a minority of children and young people in care (Jackson and Cameron, 2012). To date, only one large scale study has focused on care experienced students attending university in the UK. Cameron, Connelly and Jackson (2015) showed that young people who have been in care can succeed at university despite often having a difficult journey. This is an undoubtedly necessary and worthwhile area of study, however the evidence base on participation by care experienced young people in higher education continues to be very weak (Cameron et al., 2015). This is particularly true for Northern Ireland, where no such study has taken place. Consequently, the present study seeks to add to the literature on factors that empower and contribute to the resilience of care experienced young people in Northern Ireland who transition to higher education.

Design

A qualitative methodology using semi-structured interviews was adopted to enable an in-depth exploration of individual experiences.

Participants

Four care experienced university students took part in an interview. Participants included one male and three females aged from eighteen to twenty-five years. All participants had been in care for more than three months and ranged from year one to final year of study. Using pseudonyms these were; Abbie aged twenty-one, a final year undergraduate student who has had one foster placement lasting six years; Vanessa aged twenty-five, a first year student who had experienced approximately eleven placement changes made up of foster and residential care over a total of nine years; Hannah aged twenty-one a second year student who had been in care alongside her brother for twelve years, Hannah has had three care placements including one year spent in kinship care, a year spent in a foster placement and has spent the last ten years with her current foster family; Michael aged twenty, a second year student who has spent the last nine years with his present foster family.

Procedure

An invitation to participate was sent by the University Student Outreach Advisor to care experienced students (N=40). The logistics of the interview were arranged by letting students choose a date and time to participate, ensuring their university or personal commitments were not interrupted. Each interview took place on the university campus.

Summary of Findings

Using thematic data analysis (Braun and Clarke, 2006) three themes were identified, which capture the experiences of the participants: (1) stability and support during care and education, (2) internal motivation and (3) support during transitions to university.

1. Stability and support in care and education

In common with the literature in this area (Stein, 2008; Jackson and Cameron, 2012; Driscoll, 2013), the accounts of this sample reflected in many cases some disruption or adversity in terms of placement instability whilst in care or disruption during education.

A lot of my time in care I felt very insecure and it seemed very disorganised as well, for sure... any foster placements that I ever went to that I maybe thought were going well and then your social workers turns round and says "right we're going out for a coffee" and then the next minute there's your foster mum pulling up with all of your stuff... 11 [placements] I think I've had — Vanessa

So I missed out on primary five 'cause I had to look after my mum who was sick, and my brother who was only a baby at the time — Hannah

However, what was also evident was the ability of participants to articulate the factors that had helped them overcome such obstacles or barriers. Foster families taking an encouraging and supportive role was significant for some students. For instance, Michael considers his foster placement as having a major role in his educational success:

For me it was pure the foster home that I lived in and I've been living there now for years. Basically owe them, for just 'do your homework', giving me shit and giving me shit for years. — Michael

2. Internal motivation

Hannah acknowledges her foster parents as playing a facilitating role but, whilst this may indeed have influenced her ability to succeed educationally, she also emphasises her personal drive to succeed. Abbie consistently refers to her robust personal motivation to overcome the low expectations of others, a finding that mirrors those of Munson (2013):

I was told I could never come to uni... so then that sort of pushed me to do it myself, knowing that I could do it...if someone tells me I can't do something I prove them wrong. So, and I've done it myself like. So, I was told from the 11 plus, I was told I couldn't do anything and I've come to uni and everything then. — Abbie

What is evident, therefore, is the importance of an internal drive to succeed and overcome adversity for most of the participants. This is perhaps best exemplified in the experience of Vanessa, who disregards in-care or educational experiences as being facilitative of her educational resilience:

...I think I just got to a point where I was just like, right you know, all this bad stuff happened, maybe it wasn't in my control, but my future is. — Vanessa

3. Support during transitions to university

Transitioning to university for this sample care experienced young people appears to have been a positive experience overall. Though making no real reference to pressing difficulties, some of the participants, particularly Michael and Abbie, allude to financial problems as being a potential barrier to their continued enrolment in higher education. Nevertheless, they also speak of the financial support from the care leaver service in addressing this. The students who took part in this study view the available care leaver service as supporting their academic, financial and pastoral needs:

...all these years you've been shipped to social services and all but like I'm sitting here now basically if I need something from the university I'll contact [outreach worker]. — Michael

Conclusion

To summarise, the present study aimed to add to the existing body of literature about the experiences of care leavers currently enrolled in higher education. The findings presented here particularly highlight the supportive role of foster families, as well as an internal motivation to succeed or overcome the low expectations of others. In common with the literature in this area (Stein, 2005; Jackson and Cameron, 2012; Driscoll, 2012), the accounts of these students reflected in many cases, some disruption or adversity; be it placement instability or schooling disruption. What was also evident was their ability to articulate the factors that had helped them overcome obstacles or barriers. Indeed, the encouraging and supportive role of foster families was imminent for some students; with particular reference to Michael who appraises his foster placement as having a major role in his educational success, often disregarding his own role in his achievements. Whilst Hannah makes reference to her foster parents as playing a facilitating role in her educational journey, she emphasises her personal drive to succeed. Likewise, Abbie consistently refers to her robust personal motivation to overcome the low expectations of others, a finding that mirrors those of (Munson 2013). What is evident therefore, is the importance of an internal drive to succeed and overcome adversity for most of the participants, perhaps most intently for Vanessa, who disregards in-care or educational experiences as being facilitative of her educational resilience. Overall, this study provides a useful starting point for what should be an accumulating body of research. Future research should build upon these findings by further teasing out the factors that promote the educational resilience of care experienced children, building upon qualitative findings such as the current study, and moving towards a quantitative method. This mirrors the recommendations of Newman, Kemp and Basnett (2015) who suggest that a baseline quantitative study about care leavers who enter higher education would be valuable in this area.

Author information

Séana graduated from Ulster University in June 2016 with a B.Sc. Psychology with First Class Honours. In addition to her time at Ulster University, she worked as a peer researcher alongside a team of academic researchers in the School of Social Sciences, Education and Social Work at Queen's University on a three year study of care leavers in Northern Ireland with a mental health need and/or learning disability. Séana additionally spent a year working as a research assistant in the School of Psychology, Ulster University on two projects in the area of Experimental Social Psychology.

References

- Berridge D. (2007). *Theory and explanation in child welfare: education and looked after children*. Child and Family Social Work vol. 12, pp. 1-10. DOI: 10.1111/j.1365-2206.2006.00446
- Berridge D. (2012). *Educating young people in care: What have we learned?* Children and Youth Services Review, vol 34(6), pp. 1171 - 1175. DOI:10.1016/j.chilyouth.2012.01.032
- Braun V, Clarke V. (2006). *Using thematic analysis in Psychology*. Qualitative Research in Psychology, vol 32, pp. 77-101. DOI: 10.1191/1478088706qp0630a
- Cameron C, Connelly G, Jackson S. (2015). *Educating young people and children in care: learning placements and caring schools*. London: JKP
- Cashmore J, Paxman M, Townsend M. (2007). *The educational outcomes of young people 4-5 years after leaving care: An Australian Perspective*. Adoption and Fostering, vol 31, pp. 50-61. DOI 10.1177/030857590703100109
- Driscoll J. 2013. *Supporting Care Leavers to Fulfil their Educational Aspirations: Resilience, Relationships and Resistance to help*. Children and Society 27: 139-149. DOI: 10.1111/j.1099-0860.2011.00388

Darmody M, McMahon L, Banks J, Gilligan R. 2013. *Education of Children in Care in Ireland: An Exploratory Study*. The Economic and Social Research Institute, Children's Research Centre, Trinity College. Available from http://www.oco.ie/wp-content/uploads/2014/03/11873_Education_Care_SP1.pdf

Gilligan R. 2007. *Adversity, resilience and the educational progress of young people in public care*. Emotional and Behavioural Difficulties: 122-135-145. DOI: 10.1080/13632750701315631

Jackson, S. 2006. *In Care and After, A Positive Perspective*, Routledge, Oxford

Jackson S, Cameron C. 2012. *Leaving care: Looking ahead and aiming higher*. Children and Youth Services Review 34, 1107-1114. DOI: 10.1016/j.childyouth.2012.01.041

Jackson S, Cameron C. 2012. *Final report of the YIPPEE project: WP12: Young people from a public care background: pathways to further and higher education in five European countries*. UK: Thomas Coram Research Unit Institute of Education.

Jackson S, Ajayi S, Quigley M. 2005. *Going To University from Care*. London: Institute of Education.

Munson RE. 2013. *From Care to University: How Protective Factors and the Development of Resilience Can Contribute to the Successful Educational Outcomes of Care Leavers*. Bath University.

Newman, L., Kemp, A. and Basnett, F. Basnett (2015) Going Full Circle - The Transition from Service User to Student Social Worker. The Journal of New Writing in Health and Social Care, Vol 2(1).

Stein M. 2008. 'Resilience and Young People Leaving Care'. Child Care in Practice 14: 35-44. DOI: 10.1080/13575270701733682

Welbourne P, Leeson C. 2012 *The Education of Children in Care: A research review*. Journal of Children's Services 72:128-143. DOI: <http://dx.doi.org/10.1108/17466661211238682>



Participation in a youth mental health organisation impacts on resilience of young people

Aoife Price and Michael Feely

Introduction

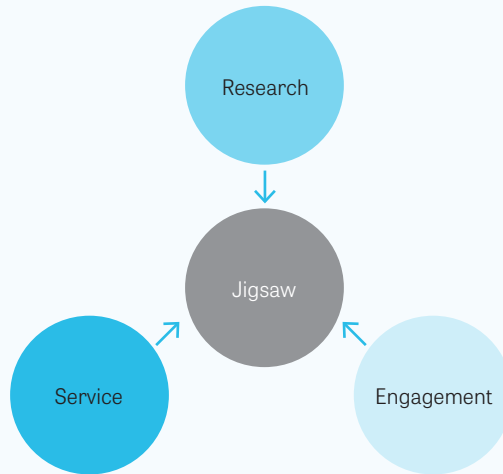
Existent literature on youth participation in mental health services is unequivocal about the benefits of participation. James (2007), for example, suggests that, in order to develop mental health services that are youth-friendly, services need to listen to young people and continually respond to what they hear. Similarly, Day (2008) contends that service user involvement in planning will lead to better quality services, responsive to the needs of, and relevant to, young people. Meanwhile Wong, Zimmerman and Parker (2010) point to the rapidly evolving nature of youth culture and propose that youth participation can help services keep in touch with young people. According to Zeldin (2004), the importance of youth participation is also increasingly acknowledged in organisational policy. Internationally we have seen a growing development in the calls to incorporate the voice of young people in the development of mental health care (Howe et al., 2011). The government in Ireland has committed to a range of activities to ensure young people are consulted and involved in decision-making, including strengthening participation in decision-making for health and wellbeing (Department of Children and Youth Affairs, 2014; 2015). The United Nations Convention on the Rights of the Child (UNCRC) (1989), which has been ratified by Ireland, advocates youth participation as a right. Article 12 of the UNCRC outlines that a child capable of forming views has a right to express those views freely. This applies to all matters that affect the child and that views must be given due weight in accordance with age and maturity. Young people are increasingly seen as assets that enable positive change and are beginning to play a significant role in many organisations.

Resilience refers to an individual's capacity to successfully adapt to change and stressful events in healthy and constructive ways (Catalano et al., 2002). Building skills that help to promote resilience in young people is important in the enhancement of their mental health (Oliver et al., 2006). Many studies on resilience conclude that young people acquire critical, adaptive skills

through participation (Olsson et al., 2003). While the importance of youth participation in mental health services is widely acknowledged, there remains a paucity of literature regarding young people's experiences of participation (Collin et al., 2012; Monson and Thurley, 2011; Howe et al., 2011). This research adds to the literature by exploring the experiences of young people on the Youth Advisory Panel (YAP) of Jigsaw (formally Headstrong) - the National Centre for Youth Mental Health - here presenting findings relating to young people's resilience. Jigsaw is working to change how Ireland thinks about and responds to young people's mental health. Jigsaw rely on research to improve its mental health services as it affords an understanding of the challenges that face young people. Through engagement, Jigsaw is changing the conversation about mental health from one of stigma and mental illness to one of openness and resilience. With the provision of services young people are achieving better mental health and well-being. The YAP is comprised of young people aged 16-25 from across Ireland who come together to work in conjunction with staff in Jigsaw to deliver on its mission. It means involving young people in decisions in an appropriate, mutually respectful and meaningful manner at every level. Some of the activities the YAP are involved in include attending and participating in team and board meetings, recruitment and induction of staff, the selection, development and design of buildings, promotion of the service and peer education.

Method

Data was collected from ten members of the YAP through semi-structured interviews and was analysed using thematic analysis underpinned by a phenomenological theoretical framework. The questions were informed by the literature review and by the information that the researcher wanted to acquire from the process. The questions were then reviewed by one of the members of the YAP to ensure they were understandable, relevant and age appropriate. According to Willig (2013), thematic analysis is a good method to analyse data



from semi-structured interviews. Thematic analysis is considered a relevant method to explore experiences, meanings, and the reality of participants (Braun and Clarke, 2006). One of its main benefits is that it can be adapted to different situations (ibid.) and is particularly suitable for addressing particular social phenomena (Willig, 2013). The researcher considered this a suitable method to analyse the data, which explored the social phenomena of the young participant's experience of being part of the YAP. Phenomenology is concerned with how people make sense of the world they are involved in (Bryman, 2012). According to Willig (2013), phenomenological research aims to elicit information about experience. Phenomenological research was selected, as the aim of the research was to find out what motivates young people to get involved and to continue involvement in the YAP.

The study was ethically approved by both Trinity College Research Ethics Approval Committee and Jigsaw. Informed consent was received from all ten participants. Participants were given a week to consider their participation. The consent form was sent to the participants along with an information sheet once expression of interest was indicated. The voluntary nature of the participation was emphasised throughout both forms and the interviewees were made aware that they could withdraw from the study at any stage without giving a reason. Participants were made aware that their participation in the study

would be kept confidential and that no identifying information would be reported. Participants were made aware of limits to confidentiality. They were informed that if they disclose that they themselves or someone else was in danger this would need to be reported to the relevant authorities. This was discussed with the Director of Clinical Governance at Jigsaw and a plan was put in place to address this. All participants were made aware that the Director of Clinical Governance was their point of contact should the interview process cause them any distress, either before, during or afterwards. They were also informed of other relevant services should they need additional support. At the time of the research, I was a member of Jigsaw's Youth Advisory Panel and thus would be considered an insider researcher (Simons, 2006). Maxwell (2009) states that personal reasons are not simply a source of bias but a valuable insight. LaSala (2003) advocates that being part of a community gives a greater understanding of viewpoint. Furthermore, he argues that being part of a community enables the researcher to formulate appropriate questions that might not occur to those from outside.

Emerging themes and discussion

A number of themes emerged from the literature relating to resilience, they are as follows:

Supportive staff

The important role played by the staff in Jigsaw in supporting the work of the YAP was viewed by the respondents in this research as an essential element to their effective participation. One participant explained how **"they respect and are willing to work with young people and not be patronising towards them"**. Another spoke of how the **"staff have always been really good in helping us do our job and getting the best out of us without being forceful"**. These findings are consistent with previous research. For example, O'Donoghue et al (2002) cites the important role that adults play in youth participation by providing guidance, information and resources. Similarly, the My World survey (Dooley and Fitzgerald, 2012) stresses that the presence of 'One Good Adult' in a young person's life is a protective factor towards their mental health.

New skills

Being a member of the YAP provided members with new skills that contributed to both personal and professional development including communication, organisational and facilitation skills. All the participants spoke about the skills they acquired. For example, one young woman stated "I have learned so much about mental health and how organisations work, I don't think college can be compared to it". Similarly, another suggested that participation in the YAP provided "an opportunity to build on your skills and learn new ones and to grow in self-confidence". Collin et al.'s study (2012) also indicates that youth participants reported an increase in new skills.

Life satisfaction

Most young people involved in the study said that their involvement gave them a sense of life satisfaction. The members of the YAP spoke of how they enjoyed the experience. They enjoyed meeting and working with the members who had become their friends. It improved their feeling of life satisfaction. One participant spoke about how he got **"enormous life satisfaction, feeling like you're doing something meaningful"**.

Youth involvement helps to foster resilience in young people when giving them a sense of belonging and connectivity (Oliver et al, 2006).

Making a difference

Making a difference was another theme that emerged from the data. One of the most important reasons for young people's participation with Jigsaw was the benefit they saw nationally and in their communities. The following are a selection of comments related to making a difference:

"Mental health is an issue that really needs to be dealt with and I think Headstrong [now Jigsaw] is one of the only organisations that give young people an opportunity to engage with it"

"I saw it as an issue, the biggest issue for young people and it affects their whole lives, and affects everyone around them".

"There was a lot of suicides and negative stigma around mental health that's why I focused more on mental health as opposed to other social issues"

When young people can see they are making a difference they are more likely to continue in the process of youth participation (Zeldin and MacNeil, 2006). Collin et al (2012) identified that young people value being part of an organisation with shared goals and values and working with the organisation to achieve its overall goals. The members of the YAP involved in this study recognised the importance of the mental health issues that affect many young people throughout Ireland. They were all passionate about contributing to making a difference and improving the mental health status of all young people.

Youth participation is not without its challenges. This paper focuses on the factors that most impacted on the young people's resilience. The overall study demonstrated the complexity of the issue with barriers and disadvantages also coming out as themes in the research. The

barriers to involvement included time, travel, lack of training and some staffing issues. The presumption by Jigsaw that all members of the YAP would engage in social media interaction was viewed as a disadvantage. Another disadvantage highlighted in the research was confusion about the role of YAP members with some people seeing them as service users and others as professionals as opposed to advisors.

Conclusion

The right of young people to be involved in issues that affect them has been increasingly recognised. This research explored the experiences of young people on the Youth Advisory Panel (YAP) of Jigsaw and here I have outlined the aspects of young people's experiences that impact on young people's resilience. Staff and the organisational culture were seen as important factors in enabling youth participation. The participants benefited from training and acquiring new skills, friendships, increased knowledge around mental health, new opportunities, increased confidence and life satisfaction. Making a difference was identified as an important element to participation. Overall, the young people were very positive regarding their involvement in the YAP and felt that it contributed to both personal and professional development. While barriers and disadvantages were identified by the participants, the benefits gained and friendships made along with the support of Jigsaw made their involvement in the YAP a positive meaningful experience that contributed to enhanced resilience.

Author information

Aoife has an MSc in Applied Social Research from Trinity College Dublin and a BA in Politics and International Relations from the University of Limerick. Aoife worked with Jigsaw for five years as a member of their Youth Advisory Panel. During this time, she worked extensively in the mental health sector. She has been awarded the Trinity Legacy Award for her project SPARKS (<http://sparksbook.org/>). This project also featured at UN World Youth Day in New York and

has been presented at conferences in Ireland and internationally. Her research interests include youth participation focusing on young people being involved in decisions that affect their lives.

References

- Braun, V. and Clarke, V. (2006) *Using thematic analysis in psychology*, *Qualitative Research in Psychology*, Vol. 3(2), pp. 77-101.
- Bryman, A. (2012) *Social research methods*, (4th Ed), Oxford: Oxford University Press.
- Catalano, R. F., Berglund, M. L., Ryan, J. A., Lonczak, H. S., and Hawkins, J. D. (2002) *Positive youth development in the United States: Research findings on evaluations of positive youth development programs*, *Prevention & Treatment*, Vol. 5(1).
- Collin, P., Rahilly, K., Stephens-Reicher, J. C., Blanchard, M., Herrman, H., and Burns, J. (2012) *Complex connections: meaningful youth participation for mental health promotion*, *Youth Studies Australia*, Vol. 31(1), pp. 36-47.
- Day, C. (2008) *Children and Young People's Involvement and Participation in Mental Health Care*, *Child and Adolescent Mental Health*, Vol. 13(1), pp. 2-8.
- Department of Children and Youth Affairs (2015) *National Strategy on Children and Young People's Participation in Decision-making, 2015 – 2020*, Dublin: Government Publications.
- Department of Children and Youth Affairs (2014) *Better Outcomes, Brighter Futures: The National Policy Framework for Children and Young People, 2014-2020*, Dublin: Government Publications.
- Dooley, B. A. and Fitzgerald, A. (2012) *My World Survey: National Study of Youth Mental Health in Ireland*, Dublin: Headstrong and UCD.

Howe, C., Batchelor, S. and Bochynska, K. (2011) *Finding our way: Youth participation in the development and promotion of youth mental health services on the NSW Central Coast*, *Advances in Mental Health*, Vol. 10(1), pp.20-28.

James, A. M. (2007) *Principles of youth participation in mental health services*, *Consumer Perspectives*, Vol. 187(7), pp.57-60.

LaSala, M.C. (2003) *When interviewing 'family': Maximizing the insider advantage in the qualitative study of lesbians and gay men*, *Journal of Gay and Lesbian Social Services*, Vol. 15(1-2), pp.15-30.

Maxwell, J.A. (2009) *Designing a qualitative study*. In Bickman, L., and Rog, D.J., *The Sage Handbook of Applied Social Research Methods*, Los Angeles: Sage Publications.

Monson, K., and Thurley, M. (2011) *Consumer participation in a youth mental health service*, *Early Intervention in Psychiatry*, Vol. 5(4), pp. 381-388.

United Nations (1989) *Convention on the Rights of the Child* (UNCRC)

O'Donoghue, J. L., Kirshner, B. and McLaughlin, M. (2002) *Introduction: Moving youth participation forward*, *New Directions for Youth Development*, Vol. 96, pp.15-26.

Oliver, K. G., Collin, P., Burns, J & Nicholas, J.

(2006) *Building resilience in young people through meaningful participation*, *Australian e-Journal for the Advancement of Mental Health*, Vol. 5(1), pp. 1-7.

Olsson, C.A., Bond, L., Burns, J.M., Vella-Brodrick, D.A., & Sawyer, S.M. (2003) *Adolescent resilience: A concept analysis*, *Journal of Adolescence*, Vol. 26(1), pp. 1-11.

Simons, H. (2006) *Ethics in evaluation*. In Shaw, I., Greene, J. and Mark, M., *The Sage handbook of evaluation*. London: SAGE Publications.

Willig, C. (2013) *Introducing qualitative research methods in psychology*, (3rd ed.), Berkshire: Open University Press.

Wong, N.T., Zimmerman, M.A. and Parker, E.A. (2010) *A Typology of Youth Participation and Empowerment for Child and Adolescent Health Promotion*, *American Journal of Community Psychology*, Vol. 46(1), pp.100-114.

Zeldin, S. and MacNeil, C. (2006) *Lessons from the Field: Engaging Youth and Adults as Partners in Organizational Governance*, *National Civic Review*, Vol. 95(1), pp. 7-14.

Zeldin, S. (2004) *Youth as Agents of Adult and Community Development: Mapping the Process and Outcomes of Youth Engaged in Organisational Governance*, *Applied Developmental Science*, Vol. 8(2), pp.75-90.



**Empowering
young women
with the rare
genetic disorder
22q11.2 Deletion
Syndrome to
share their lived
experience and
mental health
support needs**

Lorna Kerin, Fiona McNicholas and Anne Lawlor

Background

It is a key principle of mental health policy that service users' views are at the heart of mental health services (A Vision for Change, 2006). Similarly, enabling the participation of young people to engage with issues that concern them is a central tenet of contemporary Irish child and youth policy (Department of Children and Youth Affairs 2014; 2015) and indeed of international human rights policy (United Nations Convention of the Rights of the Child, Article 12, 1989). However, although young people with the genetic disorder 22q11.2 Deletion Syndrome are at known elevated risk of psychiatric disorders (Schneider 2014), their voice has not yet informed research on their lived experience of mental health nor the development of appropriate mental health services.

This research project sought to address this gap by offering a vehicle through which these young people could communicate their lived experiences and service recommendations to parents, educators, researchers, service providers and policy makers. It also aimed to support the development of mental health resilience by providing spaces for young adults to share their stories of mental health challenges and recovery. Resilience was defined simply to the young participants by the researcher as 'the ability to bounce back after times when you felt upset by your emotions, thoughts or relationships'.

Methodology

Participatory Action Research (PAR) was chosen as a methodology as it aims to empower participants by validating lived experience as a 'legitimate form of knowledge that can influence practice' (Baum, F., MacDougall, C., and Smith, D., 2006, :854). Acknowledged as a new paradigm science (Wadsworth, 1998) differing from the old paradigm of positivist science, PAR is located within a transformative research framework (Mertens, 2009), which is particularly appropriate where research aims to change

oppressive and outdated social practises, such as the exclusion of marginalised populations.

Research process

Phase one involved a collaborative grant application and subsequent project planning by a researcher, a family support organisation and a consultant psychiatrist. Ethical approval was received from UCD Human Research Ethics Committee following a full ethical review. Six female participants, aged 18-35 years and diagnosed with 22q11.2DS, were recruited to a 'Youth Expert by Experience Panel' (YEEP) through 22q11 Ireland, the national family support organisation. Written informed consent was sought from the young adult participants, and from their parents due to their mild learning disability. Additional written consent was sought regarding the use of participants' images in photographs, videos and artwork. Participant choice and ability to withdraw consent or to disguise identity was emphasised at the beginning and end of each research session. Participants emphasised that they wished their images and words to be publically shared, therefore several images have been included in this article.

Phase two involved four groups facilitated by the researcher through the use of creative arts, to support peer group cohesion and to identify emergent key themes regarding mental health. Specific Participatory Action Research (PAR) methods included:

- Somatic methods to decrease anxiety
- Narrative, arts based methods to develop group trust and creative expression
- Photo elicitation methods to facilitate voice and resistance to invisibility and silencing
- Digital storytelling methods to disseminate key messages targeted at parents, clinicians and policy makers

One of the six key themes that emerged from these creative participatory sessions was 'mental

resilience', which the group defined through discussion and consensus as the 'ability to keep going even when times get tough'. Two video-recorded focus groups were conducted to explore the six themes in more depth, co-facilitated by the researcher and the child psychiatrist.

Phase three consisted of creating a digital story of participants' discussion regarding mental health and their experience of participating in the action research process; this was collaboratively edited by group members and supported by the researcher. Participants were facilitated to present this digital story at 22q11 Ireland's national conference in November 2016 to an audience of over a hundred parents and professionals. The focus groups and reflective discussions were transcribed and analysed by the researcher. Key findings regarding the impact of participation in the participatory action research process on participants' mental health resilience are outlined below.

Key findings

Finding 1: Participation increased the protective factor of mental health awareness and literacy

Participation in a group that discussed mental health problems, treatment and mental resilience normalised talking about these issues for some participants. One young woman

expressed her realisation that she was not alone in her struggle with anxiety and stress:

We all experience anxiety and feeling stress and down from time to time." (E) Another young woman commented: "Being in a group helped me talk about how I feel. For example, we talked about thoughts and feelings and mental health, which usually we don't talk about every day. We need to talk about mental health more. — Ai

Finding 2: Participation decreased risk factors of social isolation and stigma and increased protective factors of belonging and confidence

Most participants commented on their past experience of social isolation and stigma and credited meeting others with the same genetic condition as increasing their sense of being connected and of being accepted:

Growing up I always thought I was the only one who had this syndrome, I thought wrong. I used to feel lonely and afraid. But then I met these lovely ladies who now I call friends for life" (A) Another young woman said "It was a nice feeling being in the same room as other people who have the same condition as you, and not being under pressure to have to fit in. — E

YEEP Panel Members



Several participants spoke of their increased confidence and sense of being understood due to participating in the YEEP:

It has made me feel more confident with having 22q as I didn't really like to talk about it with anyone else. But when you're in a group with people that have it, it makes it so much easier and it takes the stress off you because they know how you understand and feel about it." (A) Another young woman shared: "I feel a bit more confident since being part of the group because I am surrounded by people who are going through the same things as me and it helps that I have someone to turn to. — E

Finding 3: Participation increased acceptance of having 22q11.2DS

Initially, several participants commented on being uncomfortable disclosing their genetic condition to others and one young woman denied even having the condition. However, over the six months study period, there was a growing appreciation of the uniqueness of having 22q11.2DS and the development of a shared solidarity. As one young woman commented: *"I learned that we are the only ones that understand about us like nobody else." — N.* Increased acceptance of having the genetic condition was commented on by all, including the young woman who initially denied having 22q11.2DS: *"I found the group very worthwhile, it helped me accept my condition more." — E.*

Each participant agreed to speak about their condition and their mental health onstage at 22q11 Ireland's national conference where they encouraged other young people and their parents to be open and accepting of their condition:

Just tell everyone about 22q, it just makes life easier. You get so much help and support once you trust friends. — S

Finding 4: Participation facilitated the identification of a need for a multidisciplinary care centre to support complex health needs

The young women spoke of their frustration of attending multiple medical appointments due to the complexity of their condition and their difficulty in not being able to understand what doctors were saying due to their learning difficulties. Great emphasis was placed on the value of doctors speaking in ways that the young women could understand:

I think the clinic should be colourful and friendly and the doctors should listen to us and explain stuff in a way that we can understand. — N

The need for doctors to consult with both the patient and with the patient's caregiver was emphasised: *"I want the doctors to read the files before we come in so we don't have to explain ourselves and they should educate the new doctors who come in. Doctors should talk to the 22q patient first and then to the parent or carer or partner." — Ai.* The young women stated that they need more support with managing mental health challenges such as social anxiety and psychotic symptoms:

I think there should be doctors in the clinic to talk about anxiety as it is common for everyone with 22q and the doctors should know how to help me to cope with anxiety and big groups. Sometimes I hear sounds and voices like ghosts and I think doctors should be able to help. — K

Finally, there was consensus among all the young women about the need for a multidisciplinary care clinic to support the health, including mental health, of children and young people with this rare genetic disorder. They explained it is simply too overwhelming for them to coordinate appointments due to their complex medical needs and learning difficulties and there was deep concern and anxiety about their future ability to manage their care when their parents are no longer alive to support them. They strongly advocated that a care

coordinator should be a central support at such an integrated care clinic:

I think the clinic should have a care coordinator to help and be there at appointments. — E

Research dissemination

The YEOP, co-facilitated by the research team, presented at two major Irish conferences in 2016, to parents at the National 22q11 Ireland conference and to researchers in a 'research dialogue' at the national Children's Research Network conference. Their digital story and recommendations to establish a multidisciplinary clinic were also presented to the Minister for Disability and to the HSE National Director for Clinical Programmes in December 2016.

Conclusion

This project illustrates the benefit to seldom heard participants of engaging in an empowering participatory action research process about their mental health experience and needs. The participatory process strengthened mental health resilience by decreasing risk factors such as social isolation and stigma and increased protective factors of mental health awareness, social connectedness, confidence and acceptance of the genetic disorder. Participation also empowered participants to use their digital story to encourage greater understanding of children and young people's mental health needs among parents and to explain the need for an integrated care clinic to Irish policy makers in their own words. It is imperative that Irish mental health services not only hear the voices of these young service users but act on their recommendations to support mental health resilience through prevention and early intervention initiatives and mental health support services which are appropriate to the needs of children and young people with rare chromosomal disorders such as 22q11.2DS.

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Author information

Lorna Kerin initiated this collaborative project as founding director of Love Knowledge Consultancy, an independent social research consultancy specialising in participatory action research with children, young people and parents. Lorna is pursuing her Doctorate in Childhood Studies at Queens University Belfast and has a BA in Social Research (UL), a Higher Diploma in Integrative Psychotherapy (UCC) and a Masters in Creative Arts Therapies with at risk children (RMIT University). Lorna has recently been appointed by Tusla Child and Family Agency as Coordinator of the Dun Laoghaire-Rathdown Children and Young People Services Committee (CYPSC).

Professor Fiona McNicholas was the specialist mental health advisor to this project as Professor of Child and Adolescent Psychiatry at University College Dublin (UCD). Dr McNicholas is a Consultant in Child and Adolescent Psychiatry in Lucena Clinic, Rathgar and at Our Lady's Hospital for Sick Children, Crumlin. She trained in Psychiatry in Guys Hospital, and in Child Psychiatry in Great Ormond Street Hospital, London. She carried out a research fellowship in Stanford University, CA in 1999-2001 and returned as visiting professor in 2013/2014. She was Assistant Professor at Columbia University, NY prior to her appointment as chair in UCD in 2001.

Anne Lawlor is a co-founder and Chairperson of 22q11 Ireland, a voluntary parent support organisation that has grown its Irish membership base since 2007 to 150 families. Anne holds a B.A, M.A and a post grad Diploma and is a university guest lecturer on 22q from the parental perspective. Anne organizes annual conferences which brings parents, families and

22q clinical and academic experts together. She is passionate about raising awareness of 22qDS as a complex condition with complex needs, supporting young people with 22qDS to realise their potential and empowering families to advocate for their children.

References

Baum, F., MacDougall, C., and Smith, D. (2006) *Participatory action research*, Journal of Epidemiology and Community Health, Vol. 60 (10), pp. 854–857.

Department of Children and Youth Affairs. (2014) *Better Outcomes Brighter Futures: the National Policy Framework for Children and Young People 2014-2020*.

Department of Children and Youth Affairs. (2015) *National Strategy on Children and Young People's Participation in Decision Making*, Dublin, Government Publications Office.

Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental*

Health Policy. Government Publications Office, Dublin.

Jivraj J, Sacey LA, Newton A, Nicholas D and Zwaigenbaum L. (2014) *Assessing the influence of researcher-partner involvement on the process and outcomes of participatory research in autism spectrum disorder and neurodevelopmental disorders: a scoping review*. Autism, Vol. 18(7), pp. 782-93.

Mertens, D. M. (2009). *Transformative Research and Evaluation*, New York: Guilford.

Schneider, M. (2014). *Psychiatric Disorders From Childhood to Adulthood in 22q11.2 Deletion Syndrome* : Results From the International Consortium on Brain and Behavior in 22q11.2 Deletion Syndrome. Int Consortium Brain Behav 22q11 2. The American Journal of Psychiatry, , Vol. 171, No. 6, 06.2014, p. 627-639.

Wadsworth, Y. (1998) *What is Participatory Action Research?* Action Research International, Paper 2. Available online at <http://www.aral.com.au/ari/p-ywadsworth98.html>



International perspectives on resilience: Zambian voices

Sheila McArdle

Introduction

This paper draws upon a PhD study of Youth Civic Engagement (YCE) and resilience in Zambia, Central Africa to make the following proposition: In order to fulfil the right of young people to be heard (United Nations, 1989), researchers need to be cognisant that YCE (Sherrod, 2010) and resilience literature is northern hemisphere dominated (Ungar, 2005 and 2008). As a result, this may lead to the inappropriate imposition of northern norms of youth development, resilience and YCE in southern contexts. In practice this may undermine the cultural life systems, where sources of resilience are embedded (Masten, 2001) that sustain young people (Nsamenang, 2009; Ungar, 2008; Husain, 2006; and Mason and Bolzan, 2010) and as such is possibly "the biggest threat to child well-being" (Masten, 2001, p.237).

Lister, Smith, Middleton and Cox (2003) suggest that most adult definitions of YCE are often too restrictive to accommodate and analyse young people's understandings of how they view their own engagements. Unique insights into their lives, which are unattainable from adult only perspectives. The challenge is to fulfil the rights of young people to be heard, but to do so without de-stabilising the very culture that sustains youth in their context (Mason and Bolzan, 2010; Percy-Smith and Thomas, 2010).

Cultural context

A cultural competence approach (Husain, 2006) offers a method of meeting the aforementioned challenge. This involves three components: 1) knowledge, 2) awareness and 3) sensitivity. Prior to travelling to Zambia, the researcher conducted a literature review and met with people who had resided in Zambia to gather cultural knowledge. Awareness of power requires the prevention of bias and stereotyping. Sensitivity is the ability to act upon the knowledge and information to work in a cultural competent way during the research process.

Zambia is a post-colonial country with a dual legal system, comprising of a constitutional

system, a legacy of British rule, and customary law and the tribal governance that varies among Zambia's 73 ethnic groups (United Nations, 2006). Generally adults place an expectation upon young people to uphold the cultural traditions, which includes deference by young people towards adults and collectivism (Himonga, 2008; Caritas, 2008). The Zambian National Child Policy (NCP, 2006) recognises that children and young people face a range of adversities. These include hunger, inadequate accommodation, exposure to abuse, illiteracy, lack of basics and susceptibility to HIV/Aids and other infectious diseases (Kelly, 2008). The policy advocated for the promotion of gender equality and youth participation in national development (Sloth-Nielsen, 2008).

Research design and methodology

The aim of this PhD research is to examine Zambian youth and adult perspectives of Youth Civic Engagement, through the following objectives:

- 1 Establish local understandings of YCE
- 2 Identify existing types of YCE available in the cultural context
- 3 Locally define risk and resilience factors in relation to YCE
- 4 To identify resilience perceived to be associated with YCE

The researcher acquired ethical approval from both NUI Galway and the University of Zambia (UNZA) to progress the study. UNZA is a member of the UNESCO Child and Family Research network. Through UNZA an open recruitment process engaged a translator to enable the inclusion of potential participants who spoke only indigenous languages. UNZA also assisted with the establishment of a network of 'gatekeepers' to provide access to local communities.

For logistical reasons the research included one urban and one rural community in three out of Zambia's nine provinces, totalling six study

sites. The research participants comprised of 80 young people, aged 12-14, and 68 adults, over the age of 18. The research relied on a mixed methods approach and progressed through two simultaneous strands: 1) qualitative research with participants and 2) quantitative through mapping of existing YCE opportunities.

Qualitative Strand — Direct work with participants

This research strand incorporated two phases; A) Site contextualisation and B) Collaborative review of the draft research findings.

Phase A: Site contextualisation (Figure 1: Site contextualisation):

In each study site, cultural sensitivity led to the establishment of four focus groups arranged by age and gender. The catalyst question, "what is YCE?," was posed to initiate the focus group dialogue. To conclude the focus group, participants summarised their discussions into key points.

These points were shared at a plenary session through a collective intergenerational dialogue.

Phase B: Collaborative review (Figure 2: Collaborative review):

The researcher circulated a copy of the draft research findings to participants in all of the study sites. Subsequently, the researcher met with the research participants to critically review the draft findings and agree the final version of the findings. As a collaborative process, the validity and cultural reliability of the research was enhanced and sought to prevent potential northern bias.

Quantitative Strand — Mapping existing YCE opportunities

Through mapping of publicly available data sets, this strand accrued the number, location and type of existing voluntary Youth Services. This enhanced the contextualisation of YCE in Zambia and was used to ascertain if research participants were aware of the available services.

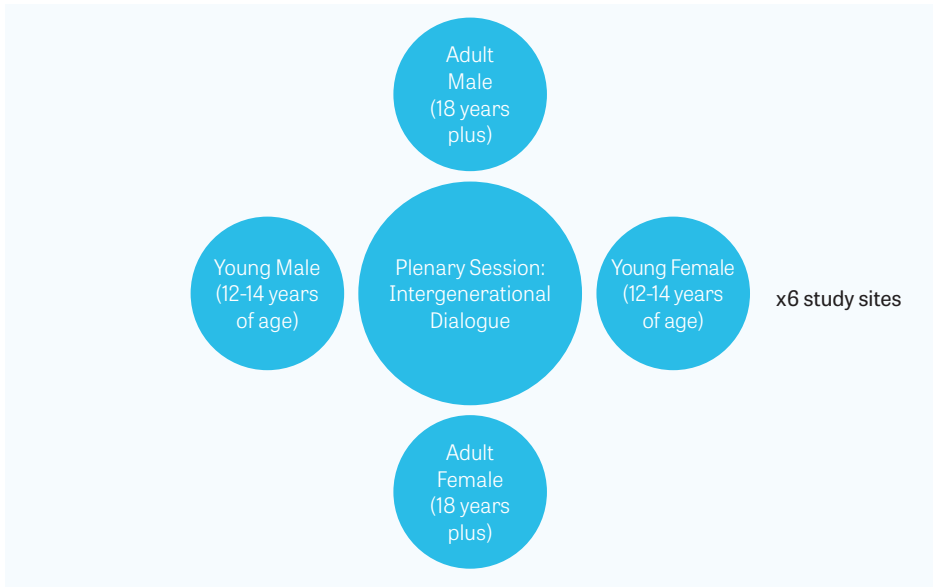


Figure 1: Site contextualisation



Figure 2: Collaborative review

Findings

A key study finding was the mismatch between adults' and young people's understandings of YCE. Adults understood YCE as political engagement, whereas young people defined YCE as "doing good things", including helping neighbours, supporting others and taking part in community life. Craig, a young male, stated that civic engagement is "something you engage in not just for yourself, but for the good of others and future generations" (McArdle, 2012, p.146).

Types of Youth Civic Engagement below illuminates the limited number of activities listed under political engagement compared to other types of engagement (Figure 3). This finding espouses Lister et.al. (2003) and Sanders and Munford's (2008) perspective that adult-only definitions are inadequate to understand how young people view their own engagements.

The mapping exercise of existing YCE services identified a total of 245 youth services within the three provinces. Similar to the participant-identified services, access to youth services were determined by age, gender, location and socio-economic background. Participants in all six study sites unanimously agreed that young people would benefit from additional YCE opportunities. Generally, it was agreed that YCE opportunities are an important source of resilience for young people within the context.

The focus groups and inter-generational dialogue identified a variety of risk and resilience factors located at individual, family, community,

societal and global level. The community level was the sole level where more resilience factors were present compared with risk factors. The education system played a pivotal role in providing access to YCE and sources of resilience at a community level. However, girls especially in rural areas were less likely to attend school than their male peers. Anna, a young female, explained "...because some they say us girls we get pregnant very early and then we have to stay a long time at our village. So they say it's better for us not to be educated and it's just better for us to get married" (McArdle, 2012, p. 167).

At the time of the research, payment of school fees from Grade 8 (approximately twelve years of age) onwards restricted progression for those unable to pay for their child's education. As a result, young people become exposed to previously un-encountered risks, i.e. seeking employment. At a vital stage of development where sources of resilience could support them, the reality was they become distanced from such supports. As way of illustration, a young person can only access out-of-school youth services at fifteen years of age. There was a dearth of services for people below 15 years of age.

From the data, gender also emerged as a significant factor impacting upon life chances. In the traditional tribal system girls start their journey into adulthood with puberty. This placed some girls in a particularly vulnerable position. In five of the six study sites, prostitution by girls was identified as YCE activity, as a necessity

Civic	Social	Cultural	Political	Economic
School:	Community:	School	Youth	Male Activities
A member of: Children's council or student council, prefect or monitor, Children' Rights Club, debate club, science club, self-evaluation club	Peer groups, Caring for others, National Independence Day celebrations	Culture club, Drama club, Poetry club, Dancing singing Arts club	Youth pressure groups	Street vending, Farming and labouring, Crushing stone
Community: Member of youth activities, clubs, scouts/girl guides, red cross, Youth Alive,	Sport/School Activities: football, netball, volleyball, basketball, baseball, athletics, rugby, tennis and swimming	Community Initiation ceremonies, language, traditional values	Mainly Adults	Female Activities in Public Markets, maids, farming and prostitution
National Youth Association, Children's press bureau, Sport for Action	Home-based games: Hide and seek, snakes and ladders, icienga, Nsolo, chase or it, game, football, chess, draughts, sigi, padda padda, riding bicycles	Spirituality/ faith: Churches of different faiths,, youth choirs, Salvation Army	Advocacy by churches	Female activities in the home: Household chores, caring for siblings.
	School: Anti-AIDs club, road and transport agency — road safety.	Evangelism, outreach, scripture union, YWCA		Rural development programmes

Figure 3: Types of Youth Civic Engagement

for the 'good' of the family, i.e. to purchase food. In this instance, young girls run the risk of sacrificing their futures for the benefit of the short-term need of the families. Culturally, prostitution based upon the concept of 'good for the family' was viewed simultaneously as both a risk and resilience factor. Such understandings can be defined as a 'dual factor'. What does this mean for developing deeper understandings of resilience? What other dual factors might exist?

Conclusion

The study process revealed that by facilitating both youth and adult voices to be heard, generational mismatches can be identified. Young people's understanding of YCE as doing 'good' moved the research beyond the narrow adult definition of YCE as political engagement. The holistic view of YCE revealed the significant contributions young people made towards their families and communities. For some young people, due to circumstances within the cultural context, these contributions are at the expenses of their own present and future well-being. The participatory research underpinned by cultural competence generated insights into YCE, along with the risk and resilience factors that determine access to YCE. It also identified associated sources of resilience and the identification of 'dual factors'.

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Currently, Sheila McArdle is an Assistant Lecturer at GMIT- Mayo contributing to the delivery of various degree programmes. In 2000, she graduated as a mature student from UCC with a Bachelor of Applied Social Science in Community and Youth Work. A career spanning almost two decades has developed a wealth of practice experience. Personal research interests include youth needs, risk and resilience, transitions, participation youth civic engagement and community sustainability. Further study at NUI Maynooth and at the Child and Family Research Centre, NUI Galway led to the completion of a Master Degree and a Ph.D. respectively.

References

- Caritas Zambia. (2008). *State of the Nation 2008*. Lusaka Zambia. Caritas Zambia
- Himonga. C. (2008). *African Customary Laws and Children's Rights: Intersection and Domains in a New Era in Sloth-Nielsen, J. (Editor). Children's Rights in Africa: A legal Perspective*. Altershot. Ashgate Publishing.
- Husain, F. (2006). *Cultural Competency, Cultural Sensitivity and Family Support* in Dolan, P., Canavan, J., & Pinkerton, J. (Eds) *Family Support as Reflective Practice*. London. Jessica Kingsley Publishers Limited.
- Kelly, M. (2008). *Education: For an Africa without Aids*. Nairobi, Kenya. Paulines Publications Africa.
- Lister, R., Smith, N., Middleton, S. and Cox, L. (2003). *Young People Talk about Citizenship: Empirical Perspectives on Theoretical and Political Debates*. *Citizenship Studies*. 7 (2), pp.235 – 253.
- Mason, I. and Bolzan, N. (2010). *Questioning Understandings of Children's Participation*, in Percy-Smith, B. and Thomas, N. (Eds). *A handbook of children, young people's participation*. UK. Routledge
- Masten, A. (2001). *Ordinary magic: Resilience processes in development*. *American Psychological Association*. 56 (3), pp. 227-238.
- McArdle, Sheila Ann (2012) *Zambian Perspectives: A participatory contextualisation of Youth Civic Engagement (YCE) from both youth and adult Zambian perspectives*. PhD Thesis, National University of Galway.
- Nsamenang, A.B.(2008). *(Mis) understanding Early Childhood Development in Africa*. *The Force of Local and Global Motives* in Garcia, M., Pence, A.& Evans,J.(Eds). *Africa's future, Africa's challenge*. USA. The World Bank.
- Nsamenang, A.B. (2009). *Challenges to developmental assessment in an African cultural setting*. SRCD-IQ African Symposium. 5th

February 2009. Canada Yaounde University and HDRC Cameroon.

Percy-Smith, B. and Thomas, N. (2010). *Emerging themes and new directions* in Percy-Smith, B. and Thomas, N. (Eds). A handbook of children, young people's participation. UK. Routledge.

Republic of Zambia (2006). *National Child Policy*. Lusaka, Zambia, Republic of Zambia.

Sanders, J., and Munford, R. (2008). *Raising Youth Voices in Community and Policy Decision-making in Leibenberg.*, L. & Ungar, M. (Eds) in Resilience in Action. University of Toronto Press Scholarly Publishing division. Canada.

Sherrod, L.R., Torney-Purta, J. & Flanagan, C.A., (2010). *Research on the Development of Citizenship: A Field Comes of Age in Sherrod, L.R., Torney-Purta, J. & Flanagan, C.A. (Eds). A Handbook of research on civic engagement in youth. New Jersey, USA. Wiley and Sons.*

Sloth-Nielsen, J. (2008). *Domestication of Children's Rights in National Legal Systems in African Contexts: Progress and Prospects* in Sloth-Nielsen, J. (Ed). Children's rights in Africa: A legal perspective. UK. Ashgate Publishers.

Ungar, M. (2005) (Ed) *Handbook for Working with Children and Youth: Pathways to Resilience across Cultures and Contexts*. London, California and New Delhi. Sage.

Ungar, M. (2008) *Resilience across Culture*. British Journal of Social Work. 38 (10), pp.218-235.

United Nations. (1989). *Convention on the Rights of the Child*. New York. United Nations.

United Nations Educational Science and Cultural Organisation. (2006). *World data on education*. 6th Edition – Zambia Retrieved from www.ibe.unesco.org/fileadmin/user_upload/archive/Countries/WDE/2006/Sub-Sa.

Research Summaries



Availability of structural and functional social supports of women in the perinatal period: instrument development

Patricia Leahy-Warren

Introduction

Social support is particularly important for new mothers. The perinatal period is a time of significant change in personal relationships, including changes in support derived from partners, other family members, and from peers (Gao et al., 2014, Leahy-Warren, 2011). It is also a time of significant personal and interpersonal change, including changes in social support derived from partners, other family members, and peers (Gao et al., 2014, Leahy-Warren, 2011).

Outcomes associated with high social support for new mothers in the perinatal period include: increased confidence (Leahy-Warren 2005), high maternal parental self-efficacy (MPSE) (Leahy-Warren et al. 2011, Shorey et al. 2014), decreased risk of antenatal (Zeng et al., 2015), and postnatal depression (PND) (Leahy-Warren et al. 2012), and an increase in infant bonding (Kinsey et al. 2014) and infant attachment (Condon and Corkindale 1998). Furthermore, low social support for mothers is associated with low family resilience (Lennon and Heaman, 2015). As mothers are predominantly the primary caregivers, low social support may have a knock on effect on the early environment for infant and toddler health and well-being, including building resilience (Lemery-Chalfant et al., 2013). In line with best clinical practice (NICE, 2017), it is incumbent upon healthcare professionals to discuss the importance of social support with pregnant women in the antenatal period and to provide opportunity for identifying strategies to enhance the availability of social support throughout the perinatal and postpartum periods. Although a number of instruments have been developed to measure social support, none are underpinned by theory in the context of perinatal infant care practices. This short paper outlines the development of The Perinatal Infant Care Social Support (PICSS) scale, which is informed by social support and social exchange theories (Leahy-Warren et al., 2011, 2012).

The PICSS scale

The PICSS scale was designed to measure both (a) structural and (b) functional social supports in the context of perinatal infant care practices (infant feeding, bathing, changing and settling). The functional support component comprises 22 items across four subscales: (1) seven items for informational support, (2) seven items for instrumental support, (3) four items for emotional support and (4) four items for appraisal support. Each item is rated by respondent mothers on a 4-point Likert Scale, with 1 indicating 'totally disagree' and 4 indicating 'totally agree'.

The structural social support scale included six items that identified the individuals who provided support to mothers. Structural social support from both formal (nurses/midwives, doctors and nannies) and informal (husband/partner, maternal parents and parents-in-law) sources was considered. Participants responded to whether they received informational, instrumental, emotional or appraisal support from any of the aforementioned sources. Participants were considered to have received formal support and/or informal structural support if they confirmed receiving any of the four support types. Each affirmative answer scored one point, and the number of affirmative answers was equated to the total score on the structural support scale. The total structural social support scores ranged between 0–24. A score of 0 meant that both informal support and formal structural support were absent from all four functional subscales. A score of 24 meant that structural support was available on all four functional subscales from all six informal and formal sources. Validity and reliability are established in studies to date (Leahy-Warren, 2005, 2011, Shorey et al., 2014). The PICSS is a coherent and valid measure of social support specific to the perinatal period in the context of parental infant care practices. Health care professionals can develop a care plan for women with low levels of structural and functional support, to meet their needs. For example, public health nurses may identify and mobilise social

support resources in the community for women in the postnatal period.

For further details please visit <http://research.ucc.ie/profiles/CO14/patricia Leahy>

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References

- Condon, J.T. and Corkindale, C.J. (1998) *The assessment of parent-to-infant attachment: development of a self-report questionnaire instrument*. Journal of Reproductive and Infant Psychology, 16(1), pp.57-76.
- Gao, L.L., Sun, K. and Chan, S.W.C. (2014). *Social support and parenting self-efficacy among Chinese women in the perinatal period*. Midwifery, 30(5), pp.532-538.
- Kinsey, C.B., Baptiste-Roberts, K., Zhu, J. and Kjerulff, K.H., (2014) *Birth-related, psychosocial, and emotional correlates of positive maternal-infant bonding in a cohort of first-time mothers*. Midwifery, 30(5), pp.e188-e194.
- Leahy-Warren, P. McCarthy, G. Corcoran, P. (2012) *First Time Mothers: social support, maternal parental self-efficacy and postnatal depression*. Journal of Clinical Nursing, 21(3-4), 388-397
- Leahy-Warren, P. McCarthy G., Corcoran, P. (2011) *Postnatal Depression in first-time mothers: Prevalence and Relationships between functional and structural social support at 6 and 12 weeks postpartum*. Archives of Psychiatric Nursing, 25 (3) pp.174-184
- Leahy-Warren, P. (2005) *First-Time Mothers: Social Support and confidence in infant care* Journal of Advanced Nursing 50 (5), pp.479-488
- Lemery-Chalfant, K., Kao, K., Swann, G. and Goldsmith, H.H. (2013). *Childhood temperament: Passive gene-environment correlation, gene-environment interaction, and the hidden importance of the family environment*. Development and psychopathology, 25(01), pp.51-63.
- Lennon, S.L. and Heaman, M. (2015). *Factors associated with family resilience during pregnancy among inner-city women*. Midwifery, 31(10), pp.957-964.
- National Institute for Health and Care Excellence (2007) *Antenatal care for uncomplicated pregnancies*. London
- Shorey, S., Chan, S.W.C., Chong, Y.S. and He, H.G. (2014) *Maternal parental self efficacy in newborn care and social support needs in Singapore: a correlational study*. Journal of clinical nursing, 23(15-16), pp.2272-2283.
- Zeng, Y., Cui, Y. and Li, J. (2015) *Prevalence and predictors of antenatal depressive symptoms among Chinese women in their third trimester: a cross-sectional survey*. BMC psychiatry, 15(1), pp.66.

Access Evidence No. 1, June 2016

CHILDHOOD ADVERSITY

Outcomes, Risks & Resilience

Access Evidence is a series of evidence reviews for front line practitioners working with children and young people.

Produced by



Childhood adversity — learning from research and practice An AcCESs evidence report

Mark Morgan, Sarah Rochford, Aisling Sheehan and Dearbhla Quinn

Introduction

AcCESs Evidence is a project developed by the Centre for Effective Services (CES) in response to their experience of working with frontline practitioners (e.g. teachers, social workers, youth workers, health workers), who encounter barriers accessing and using relevant evidence at work. In an effort to address the need for accessible evidence-informed resources, the project team summarises evidence on topics key to the lives of children, families and communities, and translates how practitioners can apply this in practice. The resources on childhood adversity, which include a literature review and summary, are the first produced by this project team.

Methodology

There were three stages to the method, in the development of the resources on childhood adversity.

Step 1: The topic and media were chosen following consultation through a survey and interviews with practitioners from the CES mailing list, working within a range of sectors, including the child and family, health and youth sectors. The response rate was ten per cent. The results indicated that the topic of childhood adversity, and the resource formats of online and printed documents, were the most popular within the options offered to respondents.

Step 2: The project team then drafted a literature review, and a summary, which were shared with a Practice Advisory Group (PAG) comprised of practitioners.

Step 3: The PAG co-produced the design and content of the resources, which included a short summary available both online and in print, and the full-length literature review, which is available online. Once the resources were launched, the PAG advised on their effective dissemination. Dissemination methods so far have included the distribution of several hundred hard copies to a range of organisations and at events. As of October 2016, there had been 40 downloads of

the summary and 70 of the literature review. CES are in the process of developing a strategy for further dissemination.

Findings and practice implications

The literature review considered the meaning, prevalence and impact of childhood adversity, as well as associated coping mechanisms, which can be utilised by children and supported by practitioners. The definition of childhood adversity utilised within the literature review was that of Hildon, Smith, Netuveli, and Blane (2008), who define adversity as "a lack of positive circumstances or opportunities, which may be brought about partially by physical, mental or social losses or experiencing deprivation or distress" (Morgan, Rochford and Sheehan 2016, p4). The literature indicated that adverse events in childhood fall under eight broad headings: poverty and debt, child abuse and neglect, family violence, parental illness and disability, parental substance misuse, parental mental health issues, family separation or bereavement (Davidson et al 2012; Spratt 2012 in Morgan et al 2016). In the first wave of the Adverse Childhood Experiences (ACE) study, conducted in the US between 1995 and 1997 among a sample of over 17,000 people, approximately two thirds of participants reported that they experienced at least one type of adversity in childhood. Additionally, 87% of those two-thirds reported experiencing multiple adversities (Dong et al, 2004).

Protective factors can help children to deal with the experience and consequences of adversity. Resilience is one such protective factor. Practitioners can play an important role in promoting protective factors, and thus resilience, through working to enhance the environment, relationships and experiences of children, and ensuring they work in connection with other services. Examples of how to achieve this are outlined in the published resources (Centre for Effective Services 2016; Morgan et al 2016, p. 25-29).

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Professor Mark Morgan is HERC's Visiting Research Fellow. He was appointed as the first Creagan Professor in St. Patrick's College, Drumcondra. His scholarship can be categorized under four broad headings: motivation and job satisfaction, substance misuse and prevention, literacy, and educational disadvantage, and are derived from his training and experience as primary teacher and social psychologist. Mark has attracted substantial funding from the Atlantic Philanthropies, enabling him to establish at St Patrick's College what has become an innovative Doctor of Education programme. Mark is working with Professor Maria Slowey on a Process Study of the Development of the Dublin Region Higher Education Authority.

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References

- Centre for Effective Services (2016) *An AcCESs Evidence Report: Childhood Adversity; Learning from research and practice*, Dublin: Centre for Effective Services
- Davidson, G., Bunting, L. and Webb, M.A. (2012) *Families Experiencing Multiple Adversities: A Review of the International Literature*. Barnardos Northern Ireland, Belfast
- Dong, M., Anda, R.F., Felitti, V.J., Dube, S.R., Williamson, D.F., Thompson, T.J., Loo C.M. and Giles, W.H. (2004). *The interrelatedness of multiple forms of childhood abuse, neglect, and household dysfunction*. *Child Abuse & Neglect*, 28(7), 771-784.
- Hildon, Z., Smith, G., Netuveli, G. and Blane, D. (2008). Understanding adversity and resilience at older ages. *Sociology of Health & Illness*, 30(5), 726-740.
- Morgan, M., Rochford, S., and Sheehan, A. (2016) *Adversity in Childhood – Outcomes, Risk and Resilience*, Dublin: Centre for Effective Services
- Spratt, T. (2012) *Why multiples matter: Reconceptualising the population referred to child and family social workers*. *British Journal of Social Work*, 42, pp.1574-1591.



Determinants of children's socio-emotional wellbeing: insights from the Growing Up in Ireland study

Mira Dobutowitsch

Aims

Recent years have seen a shift in children's pastime activities, with outdoor, physically active, unstructured and unsupervised play often replaced by indoor, relatively inactive, structured and adult-led activities. This change is attributable, in part, to the decrease in perceived 'safe' play spaces, the rise in technology-based activities (screen time) for children and the proliferation of adult-led, structured cultural activities such as arts classes, or music lessons and sports activities, like soccer or GAA (Singer, Golinkoff and Hirsh-Pasek, 2006; Elkind, 2008; McCoy, Byrne and Banks, 2012). Many authors have raised concerns about the potential impacts of these changes on children's health and wellbeing (Gray, 2011; Tremblay et al., 2011, 2015). This study aims to examine the relationship between children's pastime activities and children's socio-emotional wellbeing. The relationship between adverse life events and outcomes are also investigated.

Methods

Using data from the child cohort (age nine) of the Growing Up in Ireland longitudinal study (Williams et al., 2014), bivariate and regression analyses were conducted to investigate the relationship between screen time, organised leisure time activities (OLTA; structured cultural activities and sports activities), adverse life events, and socio-emotional outcomes, as measured by the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) and the Piers-Harris Children's Self-Concept Scale (Piers, Harris, and Herzberg, 2002). Differences and mediating effects were explored using a range of individual child, parent, family, and community variables.

Results

Amongst this cohort watching television was the most popular screen time activity; the majority of parents (66%) reported that their child watched one to three hours of television per day on average. Most children (78%) were enrolled in

one or two organised activities, but girls attended a wider variety of activities. Sports and fitness clubs were the most popular activity (75%), followed by cultural activities such as dance, music, arts and drama (47%). The majority of children have experienced at least one adverse life event during their life time (78%).

Children engaged in high levels of screen time and those not enrolled in any OLTA had more behavioural difficulties (higher SDQ scores) on average. There was no significant association between screen time and SDQ scores, but children not enrolled in any OLTA reported lower self-concept (Piers-Harris) scores on average. Children who had experienced more adverse life events scored below their peers in terms of socio-emotional well-being. While screen time, participation in OLTA and the experience of adverse life events could explain some of the variance, child and parent characteristics were stronger predictors of SDQ and Piers-Harris scores.

Conclusion

The results highlight the importance of adopting a holistic and bio-ecological model to explore the dynamic factors that impact on children's well-being. Bivariate analyses suggest that excessive screen time, no participation in OLTA and a high number of adverse life events are adversely affecting children's socio-emotional wellbeing. However, regression analyses suggest that the child's characteristics and temperament as well as relationships with family and peers are exerting greater influence on outcomes. Thus, the data reaffirm the centrality of everyday relationships in providing social support systems and the 'ordinary magic' (Masten, 2001) that helps children to thrive and build their resilience. Further analysis is needed to investigate the relationship between screen time, OLTA, adverse life events, and the relationships between the child and their surroundings. The broader socio-cultural contexts and their influence on the nature and quality of family relationships, decision making, perceived norms and ideals also needs further enquiry.

Author information

Mira is a PhD candidate in the Department of Education at Maynooth University. Her research interests are children's well-being, play, and screen time, with a focus on the impact societal changes have on childhood, including the perception of norms, evolving values and parental decision-making. For her PhD, Mira conducted secondary analyses of Growing Up in Ireland (child cohort) data, concentrating mainly on the relationship and associations between screen time, structured cultural activities, and children's socio-emotional well-being. Mira is in receipt of the DCYA Growing Up in Ireland Postgraduate Scholarship in conjunction with the IRC and a John and Pat Hume Scholar.

References

- Elkind, D. (2008) *The power of play: Learning what comes naturally*. American Journal of Play, pp. 1-6.
- Goodman, R. (1997) *The Strengths and Difficulties Questionnaire: A research note*. Journal of Child Psychology and Psychiatry, Vol. 38, pp. 581-586.
- Masten, A. S. (2001) *Ordinary magic. Resilience processes in development*. The American Psychologist, Vol. 56(3), pp. 227-238. Available online at <http://doi.org/10.1037/0003-066X.56.3.227>
- McCoy, S., Byrne, D., and Banks, J. (2012) *Too much of a good thing? Gender, 'concerted cultivation' and unequal achievement in primary education*. Child Indicators Research, Vol. 5(1), pp. 155-178. doi:10.1007/s12187-011-9118-2
- Singer, D. G., Golinkoff, R. M., and Hirsh-Pasek, K. (eds) (2006) *Play=Learning: How play motivates and enhances children's cognitive and social-emotional growth*, New York: Oxford University Press.
- Gray, P. (2011) *The Decline of Play and the Rise of Psychopathology in Children and Adolescents*. American Journal of Play, Vol. 3(4), pp. 443-463.
- Piers, E. V., Harris, D. B., and Herzberg, D. S. (2002) *The Piers-Harris Children's Self Concept Scale-Second Edition*. Los Angeles, CA: Western Psychological Services.
- Tremblay, M. S., LeBlanc, A. G., Kho, M. E., Saunders, T. J., Larouche, R., Colley, R. C., et al. (2011) *Systematic review of sedentary behaviour and health indicators in school-aged children and youth*. The International Journal of Behavioral Nutrition and Physical Activity, Vol. 8(1), Article 98. doi:10.1186/1479-5868-8-98
- Tremblay, M., Gray, C., Babcock, S., Barnes, J., Bradstreet, C., Carr, D., et al. (2015) *Position Statement on Active Outdoor Play*. International Journal of Environmental Research and Public Health, Vol. 12(6), pp. 6475-6505.
- Williams J., Greene, S., Doyle, E., Harris E., McDaid, R., Mc Nally, S., et al. (2014) *Growing Up in Ireland National Longitudinal Study of Children*. Wave 1 at 9 years, Digital Repository of Ireland, Irish Qualitative Data Archive.



Using resilience as a prism to examine children's social and emotional well-being

Emeka Okakpu, Sean McDonnell and Rebecca McHugh

Introduction

This study examines the level of resilience in two cohorts of primary-school aged children in fourth and sixth classes. The study was conducted in two areas which have been designated as disadvantaged and are also currently participating locations in the Area Based Childhood (ABC) programme- the Programme was designed in 2013 by the Government to address area-based disadvantage and to promote children's health and well-being.

Evidence suggests that many children who grow up in areas exposed to adversity do not develop behavioural problems as a result of their experience of adversity. These children could be considered 'resilient', that is they demonstrate "positive adaption... despite experiences of significant adversity" (Luthar et al., 2000, p.1). The adversity, or 'chronic stressors', which research on resilience has typically focused on includes socio-economic disadvantage and associated risks, parental mental illness, maltreatment, urban poverty and community violence, chronic illness, and catastrophic life events. Luthar et al. (2000).

Methodology

This study involved 555 children, of which over 49% (n=276) were in fourth class while 50% (n=279)¹ were in sixth class. Resilience was measured through the use of the abridged twelve-question version of the self-reporting Child and Youth Resilience Measure (CYRM-12). This measure was created by the International Resilience project and takes a socio-ecological approach to the measurement of resilience (Liebenberg et al., 2013).

Results

The mean scores for the fourth class (M=20.38, SD=2.92, Range=8-24) and sixth class (M=20.20, SD=2.83, Range=10-24) cohorts indicated high resilience score across the sample assessed.² Our findings indicated that there was no statistical significant variation between the two cohorts of children. There was no statistical significant variation between girls and boys in fourth class, [t (257)=.440, p>.05]. However, in sixth class, girls' average score was statistically significantly higher than boys' average score, [t (265).642= -2.402, p<.05].

Conclusion

Our findings show that the children assessed were resilient. Whilst no statistical significant difference was found in the average scores of girls and boys in fourth class, there was a statistically significant difference in average score across gender in sixth class where girls scored higher than boys. Further studies need to focus on exploring variables that may interact with children's resilience.

Author information

Emeka Okakpu: Emeka is a researcher at Archways. He is a qualified social worker with a master's degree in Applied Social Research. He is currently undertaking a part-time PhD study in Social Work and Social Policy at Trinity College, Dublin. His current research interest is on children's rights, health and well-being.

Sean McDonnell: Dr. McDonnell, PhD, is a psychologist and this June (2017) will complete his master's degree in neuropsychiatry at Cardiff University. Dr. Mc Donnell has many years of experience in research particularly with children and families in vulnerable communities. He is the Research and Training Manager at Archways.

¹ Figures rounded up from 49.7% (n=276) and 50.3% (n=279), respectively.

² According to the guidance of the scale developers

Rebecca McHugh: Rebecca's research interests are children's health, education, and overall well-being. She is dedicated to the production of knowledge with a practical value. Having had the opportunity to work on the Child Well-being Study while at Archways, she has recently begun working in the School of Nursing and Midwifery at TCD on the Models of Child Health Appraised (MOCHA) project which aims to provide an overview of child health systems across Europe, in order to identify optimal models. Rebecca holds an M.Sc. in International Politics.

References

Liebenberg, L., Ungar, M., and Leblanc, J.C. (2013) *The CYRM-12: a brief measure of resilience*. Canadian Journal of Public Health = Revue Canadienne De Sante Publique. Vol, 104, pp. 131-135.

Luthar, S. S., Cicchetti, D., and Becker, B. (2000) *The Construct of Resilience: A Critical Evaluation and Guidelines for Future Work*. Child Development, Vol. 71 (3), pp. 543-562.



Resilience in children with speech and language disorders: Insights from children's stories

Rena Lyons

Introduction

Resilience has been defined as a process of adaption when individuals encounter adversity and may be conceptualised both in terms of the child's capacity to cope and by the capacity of those in the child's environment to facilitate them to cope in appropriate ways (Ungar, 2015). There is evidence to suggest that children with speech and language disorders may encounter adversity in their lives. For example, such children may experience difficulties with academic performance, making friends, and they may also experience social exclusion (Feeney, Desha, Ziviani, and Nicholson, 2012; Roulstone and Lindsay, 2012). However, little is known about ways in which children negotiate negative experiences. The aim of this study was to understand the experiences of children with speech and language disorders from their own perspectives, focussing on risks to their well-being and protective strategies which may promote resilience.

Methods

Eleven nine- to twelve-year-old children with speech and language disorders were recruited using purposeful sampling. All were receiving additional educational supports. Narrative inquiry was used to generate data about their everyday experiences. Five to six interviews were carried out with each child across a range of settings with 59 interviews conducted in total. The data were analysed using analytical tools from narrative inquiry to identify themes in relation to potential risk factors to well-being and protective strategies.

Results

The themes which were identified as potential risk factors in relation to well-being were: negative feelings associated with communication impairment and disability (including undesired identities), peer relationship difficulties, concern about academic achievement, and restrictions to independence. The themes which were identified as protective strategies included:

positive identities, positive relationships, agency, and hope. Some of these strategies were child-related. For example, children were active agents and used problem-solving skills to overcome communication breakdown. Other strategies were related to the child's social network whereby constructs such as identity, hope, and independence were co-constructed, in positive and negative ways, with others. In relation to identity, children actively constructed their multiple identities and were affirmed when their desired identities (such as being competent, well-behaved, socially attractive) were affirmed by others. However, some were upset when their desired identities were challenged by others and when they were assigned labels that they considered undesirable (such as sad or special). Likewise, some children had a desire to be independent but were frustrated when this wish for independence was restricted by others.

Conclusion

This study highlights the importance of listening to children's perspectives and the important roles that others in the child's social network play in the co-construction of identities, independence, and hope. Well-being and resilience need to be conceptualised within an ecological framework so that protective strategies at both individual and social level can be strengthened to mitigate negative experiences.

For further information on this research, see Lyons, R. and Roulstone, S. (2016). Labels, identity and narratives in children with primary speech and language impairments. *International Journal of Speech-Language Pathology*, 1-16

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Rena Lyons is a Senior Lecturer in the Discipline of Speech and Language Therapy, NUI Galway. She practiced as a speech and language therapist for seventeen years before taking up a post in NUI Galway. Her clinical work was mainly with children with speech, language and communication needs. Her research interests are in the lived experiences of people with

speech, language and communication disability. She uses a range of qualitative methodologies to explore lived experiences. She is a strong advocate for listening to the voices of children with communication disability and considering ways in which these may impact on practice.

References

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-RR247-BCRP7>.

Feeney, R., Desha, L., Ziviani, J., and Nicholson, J. (2012) *Health-related quality-of-life of children with speech and language difficulties: A review of the literature*. *International Journal of Speech-Language Pathology*, 14(1), 59-72.

Roulstone, S., and Lindsay, G. (2012) The perspectives of children and young people who have speech, language and communication needs, and their parents *Better Communication Research Programme* Available online at

Ungar, M. (2015) Practitioner review: Diagnosing childhood resilience—a systemic approach to the diagnosis of adaptation in adverse social and physical ecologies. *Journal of Child Psychology and Psychiatry*, 56(1), 4-17.

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