

Peer Support Groups For Parent-Carers Of Children With ADHD: The Importance Of Solidarity-As-Care

Abstract

Parent-carers of children with complex needs often lead lives impacted by challenging constellations of disadvantage and can become enmeshed in complex and contradictory tapestries of care structures and relations. Against a backdrop of financial austerity and under-resourced or exclusionary service practices, peer support groups may become increasingly important and confer valuable benefits not available elsewhere. This paper focuses on one such group which was developed for the parent-carers of children diagnosed with ADHD, and reports on semi-structured interviews with thirteen parent-carers. Drawing upon Jeannette Pols' (2015) empirical ethics of care, we nuance and detail the care that emerged in these settings, highlighting the material and relational practices that developed. We conclude that peer support groups can offer new and vital possibilities, re-situating participants from individualised positions of burden, isolation and social exclusion to confident, positive, active connectedness, by means of an affective and effective relational process we call 'solidarity-as-care'.

Living with a Child with Complex Needs

While having a child with a disability does not necessarily lead to difficulties, a substantial body of research documents the numerous challenges that many parent-carers experience in a multiplicity of arenas, both private and public. For instance, many studies highlight the acute sense of grief, loss, guilt and burden which can be overwhelming, alongside extreme levels of social exclusion and financial disadvantage (Solomon, Pistrang, and Barker 2001; Ryan 2005; Klein & Walker 2013; Walker & Stretfield, 2012). Indeed Swain et al. (2014) suggest the concept of ‘disabling barriers’ to describe the mechanisms through which people are excluded from full participation in all aspects of civic life, including family, work and leisure (Solomon, Pistrang, and Barker 2001; Ryan 2005),

In addition, parent-carers of children with behavioural difficulties often describe feeling judged, blamed and scrutinised (Knight 2013), leading to a heightened and stressful ‘situation consciousness’ when in the public sphere (Ryan 2005). Ryan (2010) suggests that the parent-carers of children with complex needs often experience a form of ‘soft criminality’ where, through glances, stares, comments and other subtle indications, other adults continually communicate that their children’s behaviour is both unacceptable and a reflection of their own moral character. A similar form of blame and judgement was also highlighted by Becker et al. (2014) who found that the parents of children receiving mental health care often felt blamed for causing mental illness in their children through poor parenting. As such, these parent-carers are made visible as social rule-breakers who lose the privilege of civil inattention (Ryan 2005). This may then increase the challenges of being in the public sphere and therefore increases their social exclusion and isolation.

The extent of the difficulties experienced in these multiple arenas – psychological, interpersonal, financial and public - can be such that many parent-carers are routinely dependent on pharmaceutical treatments as a form of coping strategy. Indeed Walker and Stretfield (2012) found that it was ‘normal to be on antidepressants’, with sleeping pills constructed as ‘the price of being able to look after their child’. While these medications are undoubtedly useful for many parent-carers, a reliance on medical interventions to deal with non-medical difficulties indicates a lack of access to more appropriate solutions (Walker, Hart, and Hanna 2017).

This paper focuses in on one possibility, which, while not offering a solution as such, appears to confer significant benefits to parent-carers. We report on a peer support group for parent-carers of children diagnosed with ADHD and explore in detail the care practices which emerge in this setting.

Contradictions of Care

The myriad implications of living as a parent-carer of children with complex needs means that they often find themselves interwoven into a tapestry of complex and multiple care practices. The picture that emerges from interactions with education providers, social services, health services, family members, fellow parent-carers, community based organisations and the welfare state is one of complexity and contradiction.

For example, family support can play a valuable and essential role, often due to the prohibitive nature of professional care costs. However while this support is welcome, it can also be experienced as undermining, as family members may be explicitly critical of the parenting practices of the parent-carer (Walker, Hart, and Hanna 2017).

Experiences with professionals can also be similarly welcome yet negative. While they are important service gatekeepers offering essential forms of biomedical, educational and social care, the support they provide can be experienced with ambivalence. For instance, research suggests that many parent-carers report dissatisfaction regarding their interactions with the mental health system (Dixon et al. 2011), where instead of focusing on the child and their needs, clinicians focus instead on parent psychopathology, ineffective parenting and express frustration at the high level of parental mental health issues (Baker-Ericzén, Jenkins, and Brookman-Frazer 2010).

Studies also report that when entering into professional arenas of medicine, social care and education where their children's welfare is discussed, parent-carers struggle to be heard and may feel the need to exaggerate their own evidence in order to have any chance of being listened to (Moen et al. 2011). In line with this, extensive research describes parent-carers being ascribed to 'walk-on roles', in which their extensive experience and expertise is disqualified or marginalised, their observations given little weight and their concerns routinely dismissed (Reid and Weatherly Valle 2004; Pols 2015; Foucault and Gordon 1980). Valle and Aponte (2002) suggest that this is partly a result of their knowledge being considered subjective and therefore disqualified for its lack of objective 'scientificity' (Reid & Valle, 2004), privileging instead the authority of the professional. This can result in parent-carers feeling excluded from essential decisions regarding their children and

experiencing their fate as being entirely at the mercy of the professionals they encounter (Moen et al. 2011).

Studies highlight the fact that parents are more satisfied when they are able to participate in making clinical decisions and when they can use their own lived experiences to shape and support decisions regarding their children (Fiks et al. 2011). Parents often play an essential role in their child's rehabilitation (Hung et al. 2010) and notice small changes in developmental progress, thereby having some awareness over how service might be delivered more effectively (Woodcock & Tregaskis, 2008). Dewey, Crawford, and Kaplan (2003) suggest that parents are an excellent source of information on language development and that parental reports of memory, language, cognitive and motor skills are consistent with children's actual performance on psychometric assessments. Therefore the dismissive and marginalising practices of professionals with regards to parent-carers can be both frustrating to the parent-cares and detrimental to the child.

Another example of the ambivalent nature of care is related to the support received from the welfare state. Many parent-carers are entitled to Disability Living Allowance (DLA) for their children which provides extra finance for the additional costs associated with caring for a child with complex needs. Research has suggested that the positive impact of a successful application can be considerable in terms of parent's welfare and mental health (Walker and Klein 2015). However, the children's DLA form comprises a significant emotional and technical challenge and represents a daunting prospect for parents who are routinely pushed to their limits in terms of time and energy (Banks and Lawrence 2005).

Accessing services and peer support

Many young people and their families face considerable difficulties in accessing services, with data from the NHS revealing increases in referrals and waiting times, and providers reporting on the increased complexity and severity of presenting problems (Department of Health, 2015). This is despite the establishment of the National Children and Young People's Mental Health and Wellbeing Taskforce (2014) which aimed to make it easier for children, young people, parents and carers to access help and support when needed.

Research carried out in Brighton and Hove in East Sussex echoed these issues, highlighting difficulties accessing services and unclear eligibility, long waiting times for assessment and no guidance on how to manage daily life in the meantime (Walker & Stretfield 2012). Many families are required to assume highly skilled roles in advocacy, crisis management and assistance in daily living, and may have to cope with altered family expectations. Furthermore, many have to do this with few resources, little information and no training (Stephens et al. 2011).

In light of this, peer support groups can play an essential role in supporting and informing parent-carers. Solomon, Pistrang and Barker (2001) suggest that such groups can offer a sense of community, emotional support, helpful role models, a powerful and positive ideology, and provide valuable information and ideas on coping. For some they also make possible previously absent companionship, overcoming some of the social isolation and exclusion so deeply felt, and offering a sense of mastery and control. Luckstead et al. (2012) suggests that peer-run family to family support programmes show immediate benefits for attendees, including increased empowerment and decreased subjective burden. Indeed their study showed that the persistence of benefits included reductions in distress, increased

problem solving skills, coping, empowerment and knowledge. These persisted for six months after the end of the programme.

A particular benefit that can arise from such programmes is that they can exist longer term as a renewable mutual assistance resource. Referring to their peer-taught twelve week family-to-family education programme, Dixon et al. (2011) suggest that while rigorous studies on peer-based family education support have been limited, they found evidence of increased knowledge of mental illness and the mental health system and improvements in problem-solving. Using a parent-to-parent peer support befriending scheme with parents whose children have a disability or additional need, Bray et al. (2017) recently found that parent-to-parent peer support has a positive influence on parent's levels of psychological distress and their ability to cope with being a parent of a child with a disability, and acted as a catalyst for many parents to move towards a place where they could grow, flourish and thrive.

Austerity and solidarity

The reduced funding context for health and social services during the era of austerity has led to reflections on the need for alternative approaches in both delivery and content (Department of Health 2015). One response to this has been the emergence of solidarity initiatives, which have been constituted as new projects and practices of citizenship - sets of relations and imaginaries that enable the recirculation of rights and services under austerity (Cabot 2016). However 'solidarity' is a contested term, which is both over and under-utilised. There is a body of literature, mainly within the fields of ethics and politics which explore its meaning and implications (Cabot 2016), but besides the literature on social contracts which focuses on issues relating to the welfare state, few look at solidarity in relation to care. Carrabregu

(2016) suggests that with regards to the so-called ‘three pillars of society’: liberty, equality and solidarity (fraternity), the third gets by far the least attention and is seen as the least important. Solidarity tends to be commended as praiseworthy, but discarded as an optional extra, thereby downplaying its status as a moral and legal obligation. Moreover, the ways in which solidarity is described in the literature may differ strongly from how it unfolds in practice - that is, the disconnect between how solidarity should work and the messiness of everyday life (Cabot 2016).

Cabot suggests that solidarity may offer new possibilities for care in the context of austerity, and describes contemporary solidarity movements as positioning civil society as the central locus of relationships of care. Here solidarity is not constituted normatively or as an explanatory construct, but rather as fleeting practices of care in a moment where there is a move away from what ter Meulen (2015) describes as welfare state solidarity.

Rakopoulos (2016) places emphasis on ‘solidarity practices’ whereby solidarity is continuously taking shape in relation to the austerity-ridden lifeworlds of Greece’s residents following the major economic crisis. Rozakou (2016) suggests that in analysing solidarity as a social practice, it is important to foreground the people, spaces, tools, sharing of practices and tactics and routines that are constitutive of solidarity. As such, any emphasis on solidarity should pay attention to ‘the malleability and plasticity of human interactions and its resonances with spatially informed ethical imaginations’ (p.188). Through solidarity, human encounters become sites that challenge state-based definitions, boundaries and lines of power.

As parent-carers of children with complex needs are entwined in multiple relations of care, much of which is experienced as both beneficial and problematic (Walker & Stretfield 2012),

we were interested in the utility of peer support care practices oriented around carer solidarity and whether these may have value at a time when public sector funding is under continued threat. In light of the research outlining marginalisation in professional arenas, stigma in the public sphere, psychological stress and burden, social isolation and exclusion, financial difficulties and distress, we were interested in what care practices emerge in peer support spaces and what role solidarity might play in these settings.

Procedure and Participants

The Support Group

Amaze is a user-led registered charity active in the Brighton and Hove area, whose mission is to inform, support and empower parents of children with disabilities and complex needs aged 0-19 years. This project brought together a new partnership between Amaze, the University of Brighton, and the Community Child and Adolescent Mental Health Service (CCAMHS) to address the support needs of the parent-carers of young people diagnosed with ADHD.

Following recruitment through Amaze in November 2015, a focus group was held for parent-carers of children or young people who had been diagnosed with ADHD, in order to co-produce a support framework for the parent-carers. Out of this came a proposal for the development of a six session group, covering areas such as stigma, understanding ADHD, stress and resilience, parenting tips, and negotiating with schools. The project partners adapted a previously designed course which had been evaluated as a successful and effective form of facilitated peer-support (Britton & Auman, 2012). This new adapted course specifically focused on parent-carer experiences of ADHD. The authors liaised with the

Brighton Parent-carers Council (PaCC), Child & Adolescent Medical Health Emotional Wellbeing Group (CAMHEWG) and managers at Amaze and CAMHS to ensure satisfaction with the nature of the intended course delivery.

Thirteen parent-carers completed the final series of workshops which were held in a local community setting on Friday mornings over six consecutive weeks at a time that allowed school drop-offs. Parent-carers were recruited following an emailed invitation that was sent out to the Amaze mailing list across the city of Brighton and Hove. The workshops were delivered by a former Amaze worker and a Community CAMHS worker who was also a parent-carer of children diagnosed with ADHD. They were delivered in a municipal town hall in Hove, East Sussex on Friday mornings over six consecutive weeks.

With regards to evaluating the project, our aim was to develop a method of evaluation that was both sensitive and effective. For this reason we carried out semi-structured interviews prior to the workshops and following completion of the workshops. Interviews took place either at the Amaze office in Brighton or in participant's homes. The choice of location was made by the parent-carer depending on their comfort and convenience.

All interviews were audio recorded and lasted 30-45 minutes. The first interview focussed on exploring the lived experiences of the families of young people diagnosed with ADHD. The second interview explored participant's experiences of taking part in the peer-support group. The research was scrutinised and approved by the University of Brighton School of Applied Social Sciences Tier 1 research ethics panel.

Analysis

Thematic analysis was used to analyse the interviews. Thematic analysis is a form of qualitative analysis aimed at identifying, analysing and describing patterns of meaning within data. It is epistemologically flexible and adaptable, providing space for clearly articulated analytical choices oriented to the specific forms and contexts of data generated and a range of research questions (Braun & Clarke, 2006). It is ideal for semi-structured interviews where similarities and differences between accounts form key components which are then developed into themes. The primary themes which emerged were: Reasons for coming to the course; the importance of course atmosphere; changing practices not people; the value of seeing others struggle; solidarity and care. These themes shall be explored and discussed in the next section. All names have been changed throughout to protect anonymity.

Results and Discussion

Reasons for coming to the course

There were many motivations for doing the course, relating to the range of difficulties parent-carers often face. For instance, some parent-carers spoke of a desire for strategies and greater knowledge, due to feeling thrown in at the deep end with little support.

“...he can be a danger to himself and others and just can’t be left alone so it is hard work. So yeah, I think it was just being able to understand him a bit better.” Abby

“I thought it would be really helpful to meet other parents and to maybe learn strategies for dealing with a child with ADHD (and) with the tempers. I wanted to

have some support and find out how to deal with that when, when Paul flies into rages.” Ruth

Parent-carers of children with complex needs establish hierarchies of expertise that stray from the usual notions of professional authority, and instead privilege those who they recognise as sharing similar lived experiences (Solomon et al. 2001). In line with this, our participants were keen to receive support from people who were having experiences similar to theirs. The implication was that meaningful and useful strategies were assumed to be accessible only via those with personal experience rather than professionals who had come to acquire their knowledge of ADHD through static texts or less direct care work.

Parent-carers also told of experiences of isolation that had often been compounded by family members and friends who had struggled to empathise with their difficulties, and so they specifically sought support and empathy from other parent-carers. Indeed for many that was the single reason that they had turned up at the course.

“...strategies and support from other parents. I thought I would get a lot of support from people that would understand.” Julie

“...it was just, just to hear other parents talk and to have support and to be able to speak openly in front of other people that understand the problems that you’ve got.”

Donna

The importance of course atmosphere

When we look at informal support practices we often find that combinations of social relationships, people, conversations, changes of scene and shared histories of suffering are important, and the development of new ways of thinking and new practices are often only made possible by an atmosphere of compassion and warmth (Walker, Hart, and Hanna 2017). When parents spoke of the informal atmosphere, they didn't speak of it as a peripheral extra but as a central element of the impact of the course. Indeed the informal, friendly, relaxed nature of the setting was understood as essential to the course having any use for them.

“..But, yeah, I think it's a lot more it's not formal, it's a friendly relaxed atmosphere so you are far more likely to sort of talk in depth, and a little bit more openly and candid.” Pauline

“...it was informal, it was relaxed. I think informal to me, to me personally I feel informal is good cos I don't like feeling like I am back in the classroom but I feel that informal makes people more relaxed, more willing to open up and talk about things than if you're sitting behind a desk.” Nicola

Building an atmosphere was understood to be essential for people opening up and doing meaningful work and it contrasted directly with the more classroom-based 'feel' of previous statutory and professional encounters which elicited altogether different responses. In such an instance the ambience and atmosphere are not just how the setting is understood or judged, but were understood as a facilitator of change itself, as something capable of eliciting change in people's demeanour and outlook, including their willingness to connect, engage and hence

do the work of peer-support. The atmosphere here are the materials, relations and setting that hold these spaces together as sites that make possible specific kinds of care practice.

Changing practices not people

When trying to make sense of how peer support groups differ from professional encounters, it is important to consider the culture of helping interventions in which they are embedded. Many of these parent-carers had experiences of situations where they and their children became an object of intense observation, documentation and judgement. A perspective on social practices rather than cognitive change has value for parents with experience of being blamed for their children's negative behaviours and personal parenting deficits. A practice perspective implies an imminent relationship between knowledge and practice, whereby knowledge is constituted in practice, rather than a tangible asset that can be moved between professionals and individuals (Marabelli et al. 2014).

In contrast to so much of their experience with care professionals, the peer group focussed not on parental deficits that have to be remedied, but on peer-suggested social practices they might find useful. This represented a significant difference and a welcome, refreshing one. The actual changes made could be quite small, for instance the use of reward charts, or thinking through the dynamics of disciplining their child in different ways

“...and also I do reward charts as well. I find that that really helps, he's really getting it you know, getting a lot out of it. So yeah reward charts I find really, really good and I mentioned that to everybody. And you know, I think hopefully some of them have taken that on board.” Ruth

“... because she has children with ADHD and autism and she gave me quite a few strategies. She was saying that ‘don’t ever take all his money away from him’ so that he’s got something at the end of the week you know. So if he gets five pound pocket money, try and leave him a little bit so he’s always got something to keep going for.”

Julie

One of the important areas reported as being beneficial, was supporting each other to think through different strategies when communicating with professionals.

.. actually making a clear inventory of what you wanted to get out of the meetings cos I’ve never done that, I sort of go in without knowing what the meeting is about”.

Nicola

Hout, Pols, and Willems (2015) suggest that if we want to understand care, we need to focus on the details of material practices that people engage in and the way that these shape relationships and being present with one another. This group focussed on some of the everyday material tasks that shape social relations in the parent’s homes and helped them to work through different possibilities for how those tasks might be enacted and what the implications might be.

“..and he went up into his bedroom and I thought right I am going to leave it, rather than go ‘oh you’ve got to come down’. I left it and he did come down, he put his arms around me and said ‘I am sorry mummy’ he said, ‘let’s do the homework’ and I thought ‘wow!’” Donna

A focus on developing and sharing different practices around dealing with professionals, disciplining children, rethinking their children's responses, rewarding their children and coping with the reactions of other adults was described by one parent as increasing the 'mum repertoire' (Pauline). This parent nicely summed up the impact of the group in this context where she felt she had previously 'run out of mum repertoire' and hearing the accounts of what other parents had tried, including one of the facilitators, allowed for a 'rebooting' of their own capacities to work through some of the everyday challenges that they faced.

At the centre of the accounts that parents gave, although not always explicitly articulated, was the imagined presence of others who had previously been unable or unwilling to understand what their lives were like, or who had blamed the child's difficulties on 'poor parenting'. Often these responses were from people who were also engaged in some way or another in practices of care directed toward the family. These included teachers, doctors, close family relatives and friends.

"... it was about letting understanding come in cos there had been, you know, total lack of understanding about what was going on. And I just felt that this kind of represented my world getting a bit bigger". Sarah

The value of seeing others struggle

Many of the parents had come to experience profound guilt over their perceived inability to be 'a better parent' - a powerful 'feeling rule' (Hochschild 2012) for parents who believe they fall below the exacting standards of the world around them.

“...well just cos I was, I was low, I was stressed cos I was thinking ‘I am doing something wrong?’ I can’t figure out what I am doing wrong. I am doing everything I can possibly can. I am doing these things, but evidently wrong in some way... You do sort of internalise it and start to feel a bit ‘oh I’m a bit rubbish as a parent.’” Kerry

However a close reading of their accounts shows that the ‘evidently wrong’ nature of their parental response was judged on the basis of the reactions of other parents, professionals and members of their own family. Their responses were not judged against the lived experiences and parenting practices of other parent-carers in similar situations to their own. However, when that changes, a quite profound shift can happen.

Pols and Kroon (2007) speak of the importance of spaces that provide opportunities to experiment with social roles. Care practices which made possible a change in self-appraisal based on the struggle and misery of others may at first appear problematic. However in the context of the group, seeing others struggle was understood as a positive thing. This was not through a sense of malice but because it provided a lens through which to rethink their own practices, responses and behaviours. The old ‘typical’ parenting norms were gently pushed aside as new norms started to emerge, norms that they recognised in their own parenting practices.

“...one of the main things is that I, I used to feel very alone as if I was the only one going through this, and it has helped a lot to meet with other parents. And when I am having a difficult time, it’s not just me going through but I know there’s Nicola, there’s all these other parents that are having just as many difficulties as I am having. So yes it has now helped me believe that I am not a bad parent.” Donna

“..it was a relief that I was not sort of failing him.” Kerry

Solidarity and care

What became clear from the parent’s experiences on the course was that solidarity was an emergent product and central to the successful experience of the course. Here we define a clear difference between social support and solidarity. Social support may be understood as the perception and actuality that one is cared for and has assistance available from other people. Solidarity is a sense of unity and agreement of feeling or action, especially among individuals with a common interest. Our parents spoke of comradeship and implicitly evoked the growth of solidarity enabled by this setting and course.

“...and I think the biggest thing it does is it’s the support aspect: of the parents you know, comradeship, whatever you want to call it. That’s the thing, knowing, and we keep in touch.” Sarah

Research by the Joseph Rowntree Foundation (2014) focuses on the importance of a shared sense of understanding and experience often not found in relationships with professionals or family members, and where close-knit relationships and a sense of shared understanding can provide a strong basis for mutual support and act as a form of capital (Haslam et al.. 2012).

“... obviously cos of the age he is now there are different challenges etc. and stuff, a lot of it more emotional. And I felt in a way that I just really felt like I needed a little

bit of support and understanding from like, you know, people who are going through the same thing.” Pauline

“...that was good as well cos you kind of you don’t feel alone. A lot of the time you walk down the road and people look down at you and they will look at you as if to say ‘just give him a good smack’, he just needs a good hiding you know, he will never do it again. And they look at you as if it’s all your parenting and it’s yeah, I don’t know. It was just really nice to meet other people that are going through the same things I guess”. Abby

This comradeship and solidarity allowed for an emergence of different forms of citizenship and status to those that had previously been articulated through friendship and care (Harper and Speed 2013). There was a sense of a space that had opened up where voices previously silenced through practices of stigma and lack of empathy, were replaced by a sense of shared purpose and belonging in the group.

“It was a bit like an offloading, you could think ‘oh I can go there and I can just talk about it’ or ‘I can just tell them how things went’ - whether there was positives or negatives. So I really got excited about the next week’s course.” Julie

“I really enjoyed the people. The people were, were fabulous. There was a real sense of, of belonging, of, people not, not being afraid to be there and to share their emotions and then their knowledge and talk about experiences. That was good.”

Nicola

The idea of relational citizenship makes sense of citizenship in terms of being able to live successfully with others. Many institutions in modern liberal sociality position people as needing to become autonomous, self-regulating individuals (Pols 2016). However mutual support groups have many benefits that are rooted in a social and relational mode of citizenship. In Western industrialised society, discourses of disability include victimhood, powerlessness, isolation and dependency but through this course - which has since its completion transitioned into a monthly support group and a social media community site - people were enabled to experience solidarity, empathy, and to see others struggle. Through this, a form of peer-care emerged that was active, relational and oriented to everyday challenges.

“...and now I am in contact with a few of the parents, one in particular, and it’s nice because we actually support each other now. I know Julie has got a very difficult meeting coming up tomorrow and we text each other.” Abby

Therefore in summary, what parents primarily got from the course was practical information and tips, support and validation for themselves as good parents, the externalisation rather than internalisation of their difficulties, and a sense of solidarity.

Conclusions on Care

Parent-carers of children with complex needs can find themselves party to forms of care and support that are disparate, ambivalent, beneficial and damaging. All of the parent-carers in this study were managing complex mosaics of care structures and relations that were both

welcome and frustrating, supportive and undermining, sought after and excluding, empowering and dismissive. In circumstances of such complexity, an approach which prescribes ‘good’ versus ‘bad’ care misses the way that care practices for these parents are multifaceted, contradictory and intimately related to physical and relational spaces. Therefore instead of arguing for normative definitions of what constitutes good or bad care, we adopted Pols’ (2015) empirical ethics of care in order to nuance the practices of care that emerge in peer-support spaces and explore the centrality of solidarity to these care practices.

Our contention is that what emerged in our peer support groups is best described as a form of solidarity-as-care. This moves away from a focus on individual identities and instead pays attention to the multiple and nuanced ways in which care can be both provided and experienced by groups of people. Rather than position care as the exchange between a care giver and a care receiver, solidarity-as-care foregrounds the way that care can be experienced as part of a supportive collective where care is an emergent property of a series of relational exchanges between people with similar lived experiences of hardship.

The selves that emerged through the group were shaped by new forms of knowledge, inclusion and know-how which created new possibilities for living. In this framework, wellbeing and care can be understood through a relational account of what Duff (2012) calls enabling places; not as a set of entities to be acquired as internalised qualities of individuals, but instead as a set of effects produced in specific times and places, both situational and relational (Atkinson 2013). McGrath and Reavey (2015) speak of how some spaces offer a zone of possibility, where distress can be dispersed or stretched beyond the self and people can have experiences of sanctuary. We argue that just such an experience occurred in this setting.

Rakopoulos (2016, 149) suggests that ‘solidarity makes the threads of invisible reciprocation more lucid and paints them with political, collective understandings’. This Amaze group functioned as part of this process of making the invisible visible. It provided a forum for others to come and see and hear and do, and they engendered collective forms of understanding, in which ‘solidarity reaches out towards the other, resituating people in active social relations’ (Cabot 2016, 162).

Rakopoulos (2016, 143) frames solidarity as a ‘bridge concept’, relocating people in positions of relationship and interdependence, who ordinarily would be individualised and independent. This has particular resonance for the members of the Amaze group who struggle not only with the individualising tendencies of modern liberal governance experienced to varying degrees by all, but further through the social and financial exclusion, alienation and isolation effected by having a child with complex needs.

Cooke’s (1995, 337) definition of solidarity as “a feeling of connection whereby other human beings are seen as ‘one of us’ is key to what emerges in the Amaze group. Even when being mindful of the ‘romance of solidarity’ (Papataxiarchis 2016), it was clear that parents came to this group feeling isolated and alienated, and found a place where they could recognise themselves and others in the stories shared and in the materials, tools, relations and routines enacted therein.

Having a child with complex needs can entail the dismantling of a life once known, and a profound sense of loss, guilt, isolation, stress and burden. What peer groups can provide is a new set of narratives to make sense of experiences and frame a reconfigured life. This is enabled through three aspects of solidarity identified by Cabot (2016): Empathic

understanding; reciprocity; and material and affective assistance. Our findings suggest that peer support groups can offer all three, and do so within a context that is both affective and effective, providing solidary-as-care – a vital form of care that can only emerge in supportive spaces occupied by those who share similar experiences.

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