

Small Grant Proposal

Continuity of care experiences following the transition from Early Intervention Teams to Primary, Community and Continuous Care Teams in Ireland: A multi-perspective case study exploring the views of caregivers' of children with Autistic Spectrum Disorder and service providers

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Keywords

Continuity of care, health care transitions, Autism Spectrum Disorder, Chronic Illness Trajectory Framework.

Introduction and Overview of Proposed Study

This study aims to explore perspectives of 'experienced continuity of care' (i.e. the experience of coordinated and seamless care) of caregivers*1 of children with Autistic Spectrum Disorder (ASD) when they are discharged from Early Intervention Teams (EITs) and transferred to multidisciplinary Primary, Community and Continuing Care Teams (PCCCTs). Specifically, the study aims to explore caregivers' experiences of a number of

dimensions of continuity including *relational* (where one or more named health care providers are available with whom the service user and caregiver can establish and maintain a therapeutic relationship), *informational* (where information on prior events and personal circumstances is used to give care that is appropriate for each individual) and *management continuity* (the idea of consistency of management over time and in line with the service user's changing needs) in this cross- boundary context (Saultz 2003).

ASD is a complex neurodevelopmental disorder characterised by a myriad of impairments in communication, social functioning, restricted interests and other associated comorbidities (Kogan et al. 2009). Given the complexity of the condition, provision of care for the child with ASD, along with support for caregivers, involves engagement with a variety of services that cross many professional, organisational and agency boundaries (Mackintosh et al. 2012). Whilst the need for integration and coordination of these services is considered critical to ensuring a seamless care experience for the child and family, problems with coordination of services *within* teams are consistently reported within the literature and are cited as a considerable source of stress for caregivers (National Disability Authority 2014). However, despite this, there is a significant dearth of research focusing on caregivers' experiences of continuity of care when children transition from one health care team to an entirely new team of professionals situated in a different physical and infrastructural context. This study aims to address this gap in knowledge.

It is hypothesised that the transition from EITs to PCCCTs may potentially lead to what is referred to in other health and social care arenas as 'forced' or 'involuntary discontinuity' of care (Flocke et al. 1997) for children and their caregivers. Whilst the central focus will be on capturing caregivers' perspectives of continuity, the views of a range of service providers and administrators from EITs and PCCCTs will also be explored in an effort to contextualise caregivers' accounts and explore proposed solutions to any problematic experiences reported.

Aims and Objectives of the Proposed Programme of Research

The primary and central *aim* of this multi-perspective qualitative study is to explore caregivers' perspectives of experienced continuity of care following the transition from EIT services to PCCCTs in the 12 month period post transition. Service providers' perspectives will also be explored in an effort to contextualise caregivers' accounts and explore solutions to problematic experiences reported.

The specific *objectives* of the research are to explore:

1. caregivers' perspectives on *constructions* of continuity of care of relevance to this context with particular reference to informational, relationship, management, team and cross boundary dimensions.
2. caregivers' perspectives on *experiences* of these various dimensions of continuity within the 12 month period following discharge from the EIT and transitioning to the PCCCT.

3. caregivers' perspectives regarding any **problematic experiences** of various dimensions of continuity of care in this context.
4. service providers', managers' and administrators' perspectives on continuity of care in this context to **contextualise caregivers' accounts** and **explore potential solutions** to address any problematic experiences outlined in objective (iii).
5. To **disseminate findings** to all participants as well as to a variety of stakeholders with responsibility for delivery of services to preschool and school-aged children with ASD and their families.

Summary Literature Review Overview and Outline

Whilst there are literatures of relevance to many of the multidisciplinary strands of the present proposal including, for example, those highlighting different conceptualisations of continuity of care in primary health/social care teams, the complexity of presentation of children with ASD and their associated care journeys, the role and function of multidisciplinary teams in providing services for ASD, studies of caregivers' perspectives of 'experienced continuity' following discharge from one health/social care team to another in the early years (0-6 years) are almost entirely absent. Database searches for literature that relates specifically to the quadrangular relationship between ASD, caregivers' perspectives, transitions and cross boundary continuity of care in health/social care teams generated few results. In summary, the following literatures and themes have and will continue to inform the study aims and objectives and conceptual basis.

Definitions of continuity of care in primary health/social care contexts and teams

Over the last fifty years, continuity of care has consistently been referred to as a core attribute or value of health and social care services particularly in the context of primary and continuing services provided in the community (Stokes et al. 2005). This is because continuity is widely considered as an essential ingredient for improving quality in any health/social care system (Haggerty et al. 2003).

There are varying interpretations and definitions of continuity presented in the literature but these are primarily focused on the service provider perspective (Freeman et al. 2001). Despite this, there has been a recent consensus that continuity comprises three core elements, i.e. relational continuity which points to an ongoing therapeutic relationship between a service user and one or more service providers, informational continuity which means that information on prior events and personal circumstances concerning the service user is used to provide care that is appropriate for each individual, and management continuity which ensures a consistent approach to the management of a health condition that is responsive to a service user's changing needs (Saultz 2003). Other conceptualisations include that of team continuity in the case where care is provided by a

number of multidisciplinary health/social care providers and, cross boundary continuity, which occurs when a service user's care crosses health/social care organisational boundaries (Freeman et al. 2001). A final overarching conceptualisation of continuity is that of experienced continuity, i.e. the experience of coordinated and seamless services from the perspective of the service user (Freeman et al. 2001). This latter concept has received much less attention in the literature than the previously aforementioned service provider perspectives.

These dimensions of continuity are widely considered as essential ingredients for improving health care quality, particularly for those with chronic and complex health and social care problems (Servellen et al. 2006) such as is the case with ASD. Despite this there is limited literature focusing on experienced continuity of care in the context of ASD. A comprehensive search of relevant databases did not reveal a single study focusing specifically on service user' or caregivers' perspectives of experienced continuity of care in ASD in the early years. Whilst some studies exist that report on the concept of 'coordination of care' (e.g. see Sobotka et al. 2016, Carroll 2011, Brachlow et al. 2007), importantly, this is a related, yet conceptually different attribute of care as it refers to the organisation and coordination of services from the perspectives of service providers, not service users or their informal carers (Starfield 1998).

Furthermore, the role of and need for social science theory in conceptualising about constructions and experiences of continuity has been consistently highlighted (Diederiks and Bal 1997). Some sources have pointed to the need for more qualitative research with a focus on the service user's and carer's perspective, particularly that which would address continuity in terms of the potentially complex world of the service user's personal health and social care journey (Philipsen and Stevens 1997). In particular, the need for more studies focusing on the 'dynamics of health care trajectories (i.e. journeys), in context, which gives rise to changing needs' (Freeman et al. 2001) has been highlighted. It is argued that a focus on this concept of health care journey may unveil something of the processual experiences of continuity over time, particularly important in the case of those with ASD and complex needs that span many health and social care boundaries.

The complexity of ASD and associated care journeys or trajectories

Autistic Spectrum Disorder (ASD) is defined as a complex lifelong group of neuro-developmental disorders characterised by communication and social deficits, restricted interests and stereotyped patterns of behaviour (Kogan, Bloomberg and Schieve, 2007). These core deficits are present throughout life for the child with ASD but the impact and manifestation of these difficulties will differ with age, developmental and health status and with the presence of any additional disabilities or morbidities including, for example, cognitive impairment, attention deficits, sensory issues, depression, etc., that will place further restrictions on the child's ability to function and remain well (Lindgren and Doobay

2011). This complexity of presentation is associated with an accompanying high dependency on and use of a variety of health/social care services, unmet health needs, increased parental/caregiver stress and family burden (American Psychiatric Association (APA) 2013).

As ASD is a lifelong disability there is a significant need for children with ASD and their caregivers to actively engage across a continuum of services, organisations and agencies to ensure the complexity of the needs of the child and family are met (National Disability Authority 2014). This is particularly evident in the early year's period (0-6 years) which involves an extensive and complex diagnostic and early intervention process. In the Irish context, a complex care pathway or journey is in place for children in the preschool and school-aged periods. For example, in the 0-6 year period, service provision for children in the Irish system is located in what are referred to as Early Intervention Teams (EITs) involving a variety of bio-medical, therapeutic (e.g. Speech and Language Therapy-SLT, Occupational Therapy-OT), psychology (e.g. developmental and clinical psychology and counselling) and social (e.g. Social Work-SW and Social Care Practice-SCP) services. Following this period they are discharged from EIT services and undergo a transition to multidisciplinary, community- based primary health care teams referred to as PCCCTs (Carroll et al. 2013).

Whilst best practice consistently dictates an integrated, coordinated and seamless approach to care of the child with ASD and his/her family, it has been cited that current PCCCT services can vary from 'robust, comprehensive and integrative to, isolated, patchy and ineffective' (Health Service Executive 2012). This type of variation and inconsistency in service provision has been shown to be a significant source of stress for parents both in national and international contexts. For example, studies have consistently demonstrated that parents experience a lack of coordination of care in the context of ASD when it is delivered by multidisciplinary teams. This is characterised by a lack of coordination activities or plans (Sobotka et al. 2016), systemic issues and poor information sharing practices amongst professionals (Carroll 2011), geographical dispersion of members of teams and gaps in service provision (National Disability Authority 2014). Whilst these findings are valuable in informing us about coordination issues, results are only relevant to the context of care provided within single health care teams. In other words, they don't address the experience of caregivers when children transition from one health care team to an entirely different one in a new and unknown physical and infrastructural context.

Continuity of Care when children with ASD transition from one team to another

It has been noted that whilst **transitions** are perceived to be an important aspect of continuity they are rarely studied or explored in the context of ASD (Rogers and Zeni 2015). The literature search here did not reveal any published evidence on the processes, models and outcomes of transition and continuity of care experiences in ASD in the early

years. Despite this, appropriate coordination and continuity of care is said to be particularly important at times of transition from one service or team to another to ensure that the child and family does not miss out on appropriate and effective service provision (National Disability Authority 2014). Furthermore, the need for 'transition planning' when individuals with ASD are transitioning from one team to another along the care continuum has been advocated (Rogers and Zeni 2015).

Where transitions have been researched in the context of ASD, studies have tended to focus on later transitions in the ASD trajectory, such as the transition from paediatric services to adult based services (Kuhlthau et al. 2014) or on educational as opposed to health care transitions (e.g. see Shogren and Plotner 2012). Furthermore, once again, the focus on the service user's or caregiver's perspective has received much less attention than the provider perspective in this context.

In summary, the literature further highlights a significant dearth of literature exploring experienced continuity in the early years for children with ASD and their caregivers when provision of care crosses or transitions health and social care team boundaries.

Statement of Likely Impact/Contribution to Field

The intention is that this solution-focused study will specifically inform the development of recommendations about improving service user (i.e. children's and caregivers') experiences of continuity of care in the lead up to, during, and following the transition period from EIT services to PCCCT services. This information will be vital in informing the development of plans for the implementation of School Aged Disability Teams in line with HSE policy on Progressing Disability Services for Children and Young People in the Irish context (National Disability Authority 2014). Furthermore, this information will be of relevance to similar international EIT/PCCCT type services and structures. Results of the study will also provide the basis for informing a quantitative measure of continuity of care experiences or 'continuity of care index' for service users and caregivers in the context of ASD.

Furthermore, the study will make an important contribution to theoretical advancements in relation to conceptualising about continuity of care and care journeys in general and in the specific context of ASD. With some exceptions (e.g. Gallagher et al. 2013, Alegría et al. 1997, Low 2004), the vast majority of qualitative studies about continuity of care in health/social care in the management of chronic long term conditions are atheoretical, even though the need for social science theory in conceptualizing about experiences of continuity in this context has been highlighted (Diederiks and Bal 1997). Incorporation of a health-sociological theory, the Chronic Illness and Care Trajectory Framework -CICTF; Corbin and Strauss 1991, Strauss et al. 1985) explained and outlined below will make an important contribution to developing existing definitions and constructions of this highly complex and multidimensional construct.

Programme or Schedule of Work

Research Design

The proposed research design incorporates a multi-perspective and instrumental case study methodology (Yin 2003), framed in the CICTF. The design will incorporate a tiered and iterative approach to data collection and analysis.

Proposed Methodological Framework

The proposed methodological framework will be Flyvbjerg (2001) conceptualisation of case study. The case study has been highlighted as an important methodological framework in accessing service users' perspectives on health and social care (Gallagher et al. 2013). Furthermore, the methodology has previously and successfully been utilised in studies exploring the qualitative validation of continuity of care measures (e.g. Ware et al. 1999) and service users' perspectives on continuity of care in a variety of health care services (e.g. Gallagher et al. 2013, Wyke et al. 1999). Case studies are said to be beneficial where little is known about a given phenomenon (Stake 1995) as is the case with knowledge about cross boundary continuity of care in relation to ASD in this context. They also encourage a multi-perspectival approach (Orum et al. 1991) which in health services' research advocates the centralisation of the service user's perspective but also the perspectives of those who are involved in his/her care. This corresponds exactly with the intention of the present study to focus primarily on the caregiver's perspective, but also to involve providers' perspectives in an effort to contextualise caregivers' accounts and generate solutions to any problematic experiences reported.

Proposed Theoretical Framework

The intended product of the research is to gain in-depth and 'emic' (Pike 1967) insights into the perspectives of caregivers on continuity of care, using key concepts of the Chronic Care Trajectory Framework as a "conceptual lens" (Creswell 2007). In brief, the key features of the CICTF are that it highlights the service user's journey through health and social care with this concept of "trajectory". The CICTF has its epistemological origins in structural interactionism. The framework draws attention to 'trajectories' through health care experiences and settings as well as the 'work' that is required by multiple parties to manage this trajectory (Allen et al. 2004). Finally, it highlights the social-organizational context influencing this work. In summary, Strauss et al. (1985) use the term "trajectory to capture the total organisation of work done over the course of illness or disability as well as the perceived impact on those involved with care work and the organisation of this work.

Use of the CICTF offers potential for the context of ASD and health care transitioning because it was developed through extensive ethnographic work with people with chronic conditions and disabilities, their families and health care professionals (Corbin and Strauss 1991). Specifically, it is argued that the trajectory construct will provide a useful framework

for a sociological understanding of the 'work' and 'division of labour' inherent in providing a positive continuity of care experience for children with ASD and their caregivers. It is envisaged that it will provide the researcher with a means of analytically ordering the immense variety of events that occur in the continuity of care process as professionals and caregivers work to cope with and control the transition impacts for children with ASD as they cross the boundaries of care from EIT to PCCCT services.

Sequence of Stages of the Project

Study Context

This study will focus on three geographical regions that are local to the educational institute associated with this project and in which EIT services are based. This multiple case study design may provide 'heterogeneous cases' (Yin 2003) as the discharge and transition policies as well as coordination procedures inherent in each 'case' are likely to differ (personal communication with external collaborators/managers of EIT services). Currently, in these case contexts, at the age of 6 years and/or when children with ASD transition to primary school education (whichever occurs first) they are discharged from EITs and transition to PCCCTs as is the case across all HSE contexts in Ireland (Carroll et al. 2013). This occurs across Ireland. When children are discharged to PCCCTs they may be referred to any one, or more typically, a number of health/social care professionals including SLT, OT, SW, Psychology, Counsellor for Special Needs, Area Medical Officer, etc., for follow up assessment of needs and intervention. This means that following the transition to PCCCTs, care is provided in a new or several new physical location(s) and there are differing systems and structures of care and information-sharing practices in place across settings. This is a complex service configuration and requires engagement of service users and caregivers with a broad range of professionals who are unknown to the child and/or caregiver thus potentially impacting on experienced continuity of care.

Ethical Approval

Ethical approval for the present proposal has been granted by Sligo University Hospital (SUH) Research Ethics Committee which is charged with the responsibility of assessing and granting ethical approval of independent research studies conducted in the catchment area associated with the geographical context of this study. In summary, ethical procedures will follow and adhere to the educational institution's ethical guidelines and procedures as well as SUH and the Sociological Association of Ireland's (SAI) protocols with regard to informed consent, confidentiality and anonymity, data storage, overt research, right to withdrawal, informed consent etc.

Proposed phases of data collection

The present study proposes 3 inter-related phases incorporating a tiered and iterative approach to data collection and analysis.

Phase 1:

This phase will involve completion of a pilot study and early sensitising work. It will incorporate visits to the three EIT and PCCCT bases, discussions with relevant administrators and Heads of Services involved in provision of services to children with ASD and their caregivers, examination of relevant policy and practice documents in relation to discharge from EIT services and any transition planning and procedures in place when the child is transferred to PCCCT services. The purpose of this sensitising work will be to enable the researcher to familiarise him/herself with the practice and workings of the teams and the existing continuity of care processes inherent in them.

Phase 2:

This will involve conducting semi-structured interviews with caregivers in each 'case' (approx n=25) and will explore questions related to the meeting of objectives (i-iii).

Phase 3:

This will involve conducting focus groups (x 3 with n=10-12 participants) with a variety of front-line service providers working in EIT and PCCCTs, along with management and administrators in an effort to contextualise caregivers' accounts and explore potential solutions to any problematic experiences reported.

Proposed Methods**Sampling of Participants:**

Again, in line with ethical approval granted for the present study details of all children with ASD who have been discharged from the relevant EIT services and transferred to PCCCT services will be compiled and purposeful sampling will be applied to this list to capture important variables such as location (semi-urban versus rural location) and number/variety of follow-up services recommended in the discharge report (e.g therapies, psychological, social work, biomedical etc.). This information will be provided by the EIT managers in each respective EIT (personal communication with EIT managers). Purposeful (demographic) sampling will also be applied for the fieldwork with service providers and again in line with ethical approval granted. Based on the relevant research literature about health professionals' perspectives on continuity and coordination of care in ASD, a framework of important sampling parameters will be drawn up and provided by relevant management personnel. In the recruitment phase, managers will inform professionals about the study at various team meetings and will forward information leaflets to them asking for their consent for the researcher to contact them in relation to participating in the study.

Data Collection:

Semi-structured interviews (with caregivers) and focus groups (with service providers) will be used in the data collection process. Interviews will be conducted in caregivers' homes or in HSE-based PCCCT settings with one or both caregivers. These exploratory interviews will explore topics related to the research question, including experiences of any transition planning practices prior to discharge from the EIT, experiences of onward referral systems and procedures to PCCCTs, perceived 'gaps' or discontinuities in service provision following the transition, information-sharing practices across team and professional boundaries (informational continuity), perspectives on the experiences of relationship discontinuities with service providers in EIT (relational continuity) and finally, perspectives regarding potential consistency of management issues (management continuity), and proposed solutions to same. The service provider focus groups will be conducted in centralised PCCCT clinical settings.

Data Analysis:

Thematic analysis (Braun and Clarke 2006) will be conducted using the NVivo 11 software package to facilitate storage, coding and easy access to data. Reliability and validity of the results will be enhanced by incorporating independent coding practices between the researcher and supervisor (Lincoln and Guba 1985), frequent peer review meetings with all external collaborators, deviant case analysis and member checking (Miles and Huberman 1994).

Dissemination:

Results of the study will be disseminated to all participants involved in the study and made available to a variety of service providers, Heads of Services and administrators responsible for the organisation and delivery of health and social care services for children with ASD and their caregivers.

Time-frame for the Project

The timeframe for the full-time MA by research project is 24 months. The research is scheduled to commence in month 1 and will be completed by month 24.

Specific Deliverables (as indicated with *in the schedule below) are as follows:

- Literature Review: This will be ongoing throughout the project and will occur iteratively with the data collection and analysis process.
- Research Design: Finalised version to be delivered by the supervisor by end of month 6 though this will be refined and adapted throughout the programme of research where indicated.

- Identify Sites and participants: Final list and confirmation of sites and participants to be submitted to supervisor by month 7 for the caregiver phase and month 10 for service provider phase.
- Data Collection: Raw data to be collated by month 15.
- Draft thesis to be completed by month 21 with final submission in month 24 (see Table 1).

Activity/Months	1-3	4-6	7-9	10-12	13-15	16-18	19-21	22-24	Deliverable
Literature Review	X	X	X		X		X		Literature Review complete
Finalise Research Design	X	X							Research Protocols
Confirm sites/participants for both arms		X	X						Research Strategy
Conduct research activities			X	X	X	X			Raw Data
Data Analysis			X	X	X	X			Transcribed/Coded data
Write-up findings						X	X	X	Final thesis Report

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Endnotes

- *1 The term 'health care' will be used to denote 'health *and* social' care throughout this paper