Intellectual disability nursing and transcultural care
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Abstract
In today’s healthcare environment nurses’ are urged to use up-to-date research evidence to ensure better patient outcomes and inform nursing decisions, actions and interactions with patients. Within the practice setting there is an increasing challenge to provide care to patients from minority ethnic groups. In order to deliver care to different cultural groups, nurses need to recognize and empathize with patients’ belief systems, being mindful of their diverse cultural needs. This article presents the concept of transcultural care and identifies issues within intellectual disability nursing through a focus on the components identified by Capina-Bacote (2002; 2003) and Cortis (2003): cultural awareness, cultural skill, cultural knowledge, cultural encounter and cultural desire. It highlights the issues relevant nursing practice, cultural care and service provision for persons with intellectual disability from ethnic minorities in Ireland.

Key words: Intellectual disability, Transcultural care, Ethnic group, Cultural care, Ireland

Introduction
The World Health organisation (WHO) (1998) identifies that improving health levels of disadvantaged groups should reduce differences in health status between groups in countries. This statement can be conceptualised within the growing ethnic diversity of many western countries, challenging the adequacy of health professionals’ education and practice delivery to ethnic minority groups. Although transcultural nursing is not a new concept and Florence Nightingale recognized the need for cultural care even in her time (Seymour, 1954), it is seen as a formal area of study and practice focused on cultural care (caring) values, belief and practice of individuals or groups of similar or different cultures, with the goal of providing culture-specific and universal nursing care practices in promoting health or wellbeing (Leininger, 1978; Betancourt et al, 2002). Owing to the increased ethnic diversity in the Irish healthcare system, there is a need to move away from unicultural and ethnocentric approaches, where priority is given to the majority population and only marginal recognition given to the presence of other ethnic groups (Gerrish, 1997; Mitchell et al, 2002). With an increasingly diverse population, it is an ethical imperative to develop the knowledge, expertise and skills necessary to provide culturally competent care (Narayanasamy, 1999a; 1999b; Hilgenberg and Schlickau, 2002) and focus nursing on meeting individual patient needs (Narayanasamy and White, 2005).

Nurses need to understand and recognize that nursing is not culturally free, but culturally determined, or risk being guilty of ethnocentrism (Narayanasamy, 2003). Effective patient care requires the nurse to be culturally competent and provide care, not solely dependent on ethnic status, but reflective of individual requirements and preferences (Mold et al, 2005). Understanding cultural diversities is essential to safe and effective care and is an integral part of total health care (Leininger, 1978). A culturally competent nurse performs a nursing assessment using his or her knowledge and communication skills to identify patients’ cultural similarities and differences, and establishes mutual care goals (Gustafson, 2005). Care is what makes people human, gives dignity to humans and inspires people to get well; there can be no curing without care but caring can exist without curing (Leininger and McFarland, 2002). Therefore, nurses need to take responsibility for their own competence and provide cultural care to ethnic groups. This article aims to guide registered intellectual disability nurses (RNIDs) delivering care to patients from ethnic groups by identifying ethnicity, intellectual
disability and health care in Ireland and addressing the component of transcultural care outlined by Campinha-Bacote (2002; 2003) and Cortis (2003) (Box 1).

**Box 1: Concepts associated with cultural competent care.**

- Culture Awareness
- Culture Skill
- Culture Knowledge
- Cultural Encounter
- Culture Desire

(Capina-Bacote 2002; Capina-Bacote 2003; Cortis 2003)

**Ethnicity, Intellectual disability and Healthcare in Ireland**

Modern-day Ireland is a country of much ethnic diversity with 400 000 people from a variety of cultures (Central Statistics Office (CSO), 2007). Many people from minority ethnic communities have different cultural needs and belief systems than those of the indigenous population (Narayanasamy 2005) requiring health care which is mindful of their diverse cultural needs (Duffy, 2001; Cortis, 2003). Minority ethnic communities in Ireland include the Traveller community (an indigenous minority ethnic community with a distinct culture and history of nomadism), asylum seekers, refugees and migrant workers and their families. Despite Ireland’s ethnic diversity, it is difficult to identify people with disabilities from minority ethnic communities as they are excluded from the two main sources of population information: the CSO and the national intellectual disability (NIDD) and national physical and sensory disability (NPSDD) databases held by the health research board (HRB).

General statistics regarding intellectual disability in Ireland identify 26 066 people on the NIDD (Kelly et al, 2010). However, the CSO (2008) indicate 50 400 people in Ireland have a diagnosis of disability in their national disability survey (NDS). The reasons for differences in the statistics from the NIDD and NDS are identified in Table 1. However, although there is an absence of statistics, the authors are aware of patients from ethnic minorities within intellectual disability services through their work. This raises the questions; how do RNIDs support people from different cultures and how do they draw on existing transcultural care evidence and produce further research evidence for practice rather than relying on practice wisdom, where the nurse solely operates from their practice knowledge (Doody and Doody, 2011).

**Table 1: Reasons for different statistics between the NIDD and NDS**

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<tr>
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<th>National Intellectual Disability Database</th>
<th>National Disability Study</th>
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<tr>
<td><strong>Definition used</strong></td>
<td>The NIDD definition is based on the WHO International Classification of Diseases, Tenth Edition (ICD-10) (WHO 2007).</td>
<td>The NDS definition is based on the WHO International Classification of Functioning (ICF) (WHO 2001).</td>
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<tr>
<td><strong>Data collection method</strong></td>
<td>The NIDD based their data collection on the fact that a person was assessed by a multidisciplinary team, and his/her level of intellectual disability identified (mild, moderate, severe or profound).</td>
<td>The NDS based their data on whether or not the individual had a diagnosed of intellectual disability and was self-interpreted in a guided interview context.</td>
</tr>
<tr>
<td><strong>Criteria for registration</strong></td>
<td>The NIDD registers data only on individuals with an intellectual disability for whom specialised health services are being provided or who, following a needs assessment, are considered to require specialised services in the next five years.</td>
<td>The NDS included all individuals who defined themselves as having an intellectual disability, regardless of whether they were in receipt of or requiring an intellectual disability services.</td>
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At a national level, strategies and reports within Ireland have developed to address cultural diversity and healthcare delivery (Table 2). Additionally, there have been six annual policy reports on migration and asylum (Joyce, 2010) as well as the development of the Irish Human Rights Commission (IHRC, 2010), which reports issues of racial discrimination, asylum seekers and travellers as an ethnic minority. However, only the Health Services Intercultural Guide (HSE, 2009) acknowledges disability within cultural groups, identifying the potential for collaborative work to recognize and address healthcare needs specific to disabled service users from diverse cultures and ethnic backgrounds (HSE, 2009). This collaborative working is essential in both service delivery and future planning of care delivery. With the absence of statistics regarding intellectual disability within ethnic groups, it may be expected that a profile of non-disabled youth population exists, however, there is a likelihood that disability will emerge as they have children (HSE, 2009).

Table 2: National strategies/reports relating to ethnic minorities in Ireland

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<thead>
<tr>
<th>Strategy / Report</th>
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<tr>
<td>National Health Strategy – Quality and Fairness</td>
<td>Department of Health and Children (DoHC 2001)</td>
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<tr>
<td>Primary Care Strategy</td>
<td>Department of Health and Children (DoHC 2001)</td>
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<tr>
<td>Traveller Health a National Strategy 2002-2005</td>
<td>Department of Health and Children (DoHC 2002)</td>
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<tr>
<td>Cultural Diversity in the Irish Health Care Sector: Towards The Development of Policy and Practice Guidelines for Organisations in the Health Sector</td>
<td>National Consultative Committee on Racism and Interculturalism and Irish Health Services Management Institute (NCCRI and IHSMI 2002)</td>
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<tr>
<td>Migrant-Friendly Hospitals Project</td>
<td>Ludwig Boltzmann Institute (2005)</td>
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<td>On Speaking Terms: Good Practice Guidelines for HSE Staff in the provision of interpreting services</td>
<td>Health Service Executive (HSE 2007)</td>
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<td>Transformation Programme</td>
<td>Health Service Executive (HSE 2007)</td>
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<tr>
<td>Health Services Intercultural Guide: Responding to the needs of diverse religious communities and cultures in healthcare settings</td>
<td>Health Service Executive (HSE 2009)</td>
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Culture awareness

Cultural awareness recognizes the specific needs of different groups, where healthcare providers appreciate and become sensitive to the values, beliefs, practices and problem-solving strategies of their patients’ cultures (Campinha-Bacote, 1999; Cortis, 2003). Observing the behaviours of others through one’s own personal value and beliefs system allows for more insightful interpretation of behaviour (Campinha-Bacote, 2003). By recognizing one’s own biases, one can learn about or remove unintentional influences. This awareness process is essential because people have an unconscious tendency to be ethnocentric, judging others by using their own group as the standard (Cortis, 2003), or imposing their beliefs, values, and patterns of behaviour on another culture (Leininger, 1978; Campinha-Bacote, 2003). Within intellectual disability, RNIDs have already moved from an illness-based model of disability to a social model, where disability is seen as a problem that exists within the environment rather than the person. Effective interactions take place when the RNID develops personal awareness of his or her thoughts and feelings surrounding
disability and culture. The RNID should ask whether their actions support stigma and isolation and devalue people with disabilities from another culture or whether they are sensitive to the differences of this population in a manner that supports and listens to the points of view of the individual and their family? Practitioners intent on providing care in line with a more equal and sensitive awareness of individual differences need to critically examine the frameworks they employ and how they can distort outcomes (Jukes and O’Shea, 1998a) when working with ethnic groups. Generally, it is acknowledged that there is a low uptake of services by people with intellectual disability from minority ethnic communities (Begum, 1995; Summers and Jones, 2004). Barriers include: language and communication difficulties (Iacono and Davis, 2003); lack of accessible information (Cumella and Martin, 2004); lack of knowledge around culture and religious needs (Seeleman et al, 2009); racism in service delivery and negative past experiences (Summers and Jones, 2004); and the experience of significant stress with little knowledge or understanding of intellectual disability by the health professional (O’Hara, 2003). Therefore, a lack of cultural competence may inadvertently indicate discrimination, value judgments, or a lack of understanding regarding the worth of people with intellectual disability (Mencap, 2004).

**Cultural skill**

Cultural skill is the ability to collect relevant cultural data regarding the patient’s presenting problem as well as accurately performing a culturally-based assessment (Campinha-Bacote, 2002). Therefore, nurses need to learn how to conduct cultural assessments. Leininger (1978) identifies cultural assessment as a systematic appraisal or examination of individuals, groups, and communities based on their cultural beliefs, values, and practices to determine explicit needs and intervention practices within the context of the people being served. To perform cultural assessments, RNIDs should know how their ability to conduct an accurate and appropriate assessment is influenced by a patient’s physical, biological, and physiological variations (Campinha-Bacote, 2003). The RNID must remember that conducting a cultural assessment is more than asking a list of questions; it must be done in a culturally sensitive manner and by remaining non-judgmental to the responses given. Although conducting cultural assessment of ethnically diverse patients is particularly important, all patients need and deserve a cultural assessment (Cortis, 2003). This will prevent healthcare providers from assuming that no cultural differences or potential barriers to care exist based on the patients looking and behaving much the same as themselves (Campinha-Bacote, 2003). RNIDs already operate from a biopsychosocial educational model (Sheerin, 2004) within their assessment and care planning/delivery; they assess people on an individual basis based on their unique individual needs. Operating in a cultural skilled manner means RNIDs make use of their existing skills of seeing the diversity and uniqueness of each individual and their family. Within transcultural assessments, RNIDs need to consider the quality of the interaction with individuals, not just the content or concepts of the tool used (Jukes and O’Shea, 1998a) in order to reduce cultural bias. Awareness of one’s own cultural worldview, attitude towards cultural differences, knowledge of different cultural practices and worldviews, and cross-cultural skills are essential to reducing cultural bias and developing cultural competence which results in the ability to understand, communicate, and effectively interact with people across cultures.

**Culture knowledge**

Cultural knowledge is the process of seeking and obtaining a sound educational foundation about diverse cultural and ethnic groups (Campinha-Bacote, 2003) and their health-related
beliefs and values (Cortis, 2003). Understanding the patient and family worldviews explain how they interpret their disability and how it guides their thinking, doing, and being. However, when obtaining cultural knowledge, it is vital to be aware of variation which occurs within cultural groups (intracultural) as well as the variation that takes place across cultural groups (intercultural) (Campinha-Bacote, 2002). No individual is a stereotype of one’s culture of origin, but rather a unique blend of the diversity found within each culture, the accumulation of life experiences, and the process of acculturation to other cultures (Cortis, 2003). Therefore, RNIDs must develop skills to conduct a cultural assessment with each patient and understand disease incidence and prevalence among ethnic groups. Without this knowledge, diagnostic overshadowing may occur (Drainoni et al, 2006); this is when health issues are seen as part of the patient’s disability rather than the health professional seeking potentially treatable causes (Mason and Scior, 2004). This knowledge is essential in effective nursing practice as although illnesses or conditions may occur in any individual, people with intellectual disability experience have different patterns of health (Krahn et al, 2006; Melville et al, 2009). Additionally, the range and spectrum of disability is vast so similar to the intracultural variations in ethnic groups, there will be a wide variation between specific conditions and ranges of disability. Here, the RNID needs not only to be knowledgeable of patterns of illness and associations between particular conditions and syndromes, but also to broaden their knowledge to particular patterns and illnesses associated with ethnic groups. Cultural competence is achieved by education and exposure through practice. It leads to therapeutic competence and is viewed as a process, not as a means to an end (Jukes and O’Shea, 1998b).

**Cultural encounter**

Cultural encounter is the process which encourages the nurse to directly engage in face-to-face interactions with patients from culturally diverse backgrounds. Directly interacting with patients from diverse cultural groups will refine or modify one’s existing beliefs about a cultural group and will prevent possible stereotyping (Campinha-Bacote, 2003). However, interacting with few members of a specific group will not make one an expert on this cultural group. These individuals may or may not represent the stated beliefs, values and practices of that specific cultural group because greater variation may exist within (intracultural) than across (intercultural) cultural groups (Cortis, 2003). Interacting directly with patients with intellectual disability to refine or modify one’s existing beliefs regarding a cultural group is extremely important. Face-to-face experiential encounters can validate, negate or contradict book knowledge the nurse may have learnt about a cultural group. Failure to interact directly may result in stereotyping and a failure to develop and convey a range of verbal and non-verbal responses accurately and appropriately. These activities can be challenging, however, as the RNID has to continually depend on non-verbal communication styles in their daily work their skills may be transferable in working with people from different cultures. Nurses must continually strive to work collaboratively and effectively within the context of an individual, family, or community from diverse cultural backgrounds (Jukes and O’Shea, 1998b). Additionally, we need to view the barriers within transcultural care, not as resulting from patients’ cultures, but from the values and beliefs inherent in our own biomedical culture, insufficient professional training, and care systems (Tripp-Reimer et al, 2001) as cultural care is located within the nurse-patient relationship and involves respect and negotiation of culturally-sensitive practices (Gustafson, 2005). Recognizing patient needs is an important aspect of transcultural care and expression via familiar language including attention to non-verbal communication is essential (Royal College of Nursing, 1998; Narayanasamy, 2002).
Cultural desire
Cultural desire is seen as the motivation of the nurse to engage in the process of becoming culturally aware, culturally knowledgeable, culturally skilful, and seeking cultural encounters. It has been said that people don’t care how much you know, until they first know how much you care (Campinha-Bacote, 1999). It is not enough for the healthcare provider to merely say they respect a patient’s values, beliefs, and practices or to go through the motions of providing a culturally specific intervention that the literature reports is effective with a particular ethnic group. What is of grave importance is the healthcare provider’s real motivation or desire to provide care that is culturally responsive. Cultural desire includes a genuine passion to be open and flexible with others, to accept differences and build on similarities, and to be willing to learn from others as cultural informants. Berlin and Fowkes’ (1982) LEARN Model or Narayanasamy’s, (2002) ACCESS Model (Table 3) are considered to be useful and practical as they are action-centred to facilitate the planning and implementation of culturally congruent care that is sensitive and compassionate in nature.

Table 3: LEARN Model and ACCESS Model

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<td>L – Listen - The nurse must first listen to the patient's problem in a non-judgemental manner.</td>
<td>A – Assessment - Cultural assessment to enhance nurses’ understanding of the patient’s health beliefs and practices.</td>
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<tr>
<td>E – Explain - The nurse to explain his/her perception of the problem.</td>
<td>C – Communication - The crux of transcultural care is communication nurses need to be aware that groups vary widely in their ideas about appropriate body stances and proximities, gestures, language, listening styles, and eye contact.</td>
</tr>
<tr>
<td>A – Acknowledge - The nurse to acknowledge the differences between the two perceptions of the problem and the similarities</td>
<td>C – Cultural negotiation and compromise - Transcultural therapeutic interventions need cultural negotiation and compromise. This requires an understanding of how the patient views and explains the problem requiring nurses to become more aware of aspects of other cultures.</td>
</tr>
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<td>R – Recommendations - The nurse must make recommendations which involve the patient.</td>
<td>E – Establishing respect and rapport - Establishing respect and rapport evokes feelings of being valued producing more positive effect. Nurses can portray a genuine respect for the patient as a unique individual with needs that are influenced by cultural beliefs and values. Enabling clients to maintain their self-respect leading to better self-esteem creating a positive nurse-patient relationship, fostering an atmosphere of trust in which a therapeutic relationship will be continued.</td>
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<td>N – Negotiate - The nurse is to negotiate a treatment plan, considering that it is beneficial to incorporate selected aspects of the patient's culture into the plan.</td>
<td>S – Sensitivity - The primary concern of health care is to understand and deliver diverse culturally sensitive care to diverse cultural groups. For nursing interventions to be effective, it is paramount that nurses show sensitivity to all aspects of patients’ needs as well as the communication process involved.</td>
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<td></td>
<td>S – Safety - Patients need to derive a sense of cultural safety and nurses need to avert actions that diminish, demean or disempower the cultural identity and wellbeing of an individual. Therefore, culturally safe nursing practice promotes actions which recognize, respect and nurture the unique cultural identity of individuals, and ‘safely meet their expectations and rights.</td>
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RNIDs need to take account of the particular needs and values of people from different minority ethnic communities. This can be addressed by partnership with minority ethnic community groups to influence practice planning, monitoring and evaluation. Current philosophy of intellectual disability care is underpinned by four key principles: rights, independence, choice and inclusion (Department of Health (DH), 2001). However, these concepts need to be developed with ethnic communities as they may run counter to the values of collectivism and close family relationships that exist in some communities. Restrictive attitudes towards disability within minority ethnic communities and in the wider context need
to be addressed, through providing more information about procedures and services available in order to develop ways of enhancing empowerment within service delivery; Box 2 identifies some suggestions from the authors.

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Box 2: Developing empowerment in services.

- Services identify how many people should be and are accessing services.
- Services evaluate how well their services are serving individual and family needs.
- A partnership approach between services and community groups.
- People with more complex needs are properly included.
- Families and other people who know the people well are listened to.
- Time and resources are invested in developing communication skills in services.
- Information is accessible and in an appropriate manner/language.
- Services take account of individual needs and values.
- Advocacy is developed.
- Restrictive attitudes towards disability within minority ethnic communities are addressed.
- Increased participation for people with intellectual disability from minority ethnic communities and their families occurs in service planning.

**Conclusion**

The success of healthcare provision depends on its ability to respond to the needs of individuals (Mold et al, 2005). Transcultural care places a responsibility on nurses to consider culture in approaches to health care (Narayanasamy and White, 2005), as it is pivotal to the provision of effective, safe and total health care (Leininger, 1978). Culturally competent nurses will not effect change on purely personal changes in outlook, unless their focus is complemented by nursing policies and the broader healthcare structures of which nursing is a part. Awareness does not eliminate the need to remove racist practices and attitudes from mainstream healthcare provision and services need to develop accessible and appropriate integrated services to meet the needs of all members of the community. Good quality care requires an understanding of ethnic and cultural identity and its impact on care as well as the knowledge that many aspects of our lives that we regard as normal and universal are in fact cultural and not ‘normal’ to people of other cultures. Though cultural diversity has been acknowledged in Ireland, there is little research pertaining to disability within cultural groups. Overall, the invisibility of minority ethnic people with disabilities in Ireland is exacerbated by the lack of data. Although there has been progress regarding the collection of data on disability, the identification of ethnic groups of people with disabilities is absent from national and health data monitoring systems, making it difficult to proactively plan care delivery to meet the needs of this group. However, this affords services/researchers the potential for
collaborative work to identify and address the healthcare needs specific to disabled service users from diverse cultures and ethnic backgrounds and create an extensive database of healthcare information about culturally determined aspects of health, illness and care. Using cultural assessments would enable an accurate identification of needs based on the person’s thinking and behaviour, leading to appropriate rehabilitation plans, holistic care and healing and a tailored service.

**Key points**

- Cultural diversity is increasing in today’s society.
- Nurses need to be able to respond to the changing/individual care needs of specific groups of people – this can be addressed by identifying:
  - Am I aware of my personal biases and prejudices.
  - Do I have the skill to conduct a cultural assessment in a sensitive manner.
  - How many face-to-face encounters have I had with clients from this diverse group.
  - People with intellectual disability often are double disadvantaged when they are from a minority ethnic group.

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