Can ICT bridge the gap between research and practice to support the

early identification of Autism?

An exploratory study.

Nuala Smyth

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Declaration

I declare that the work described in this dissertation is,

except where otherwise stated, entirely my own work,

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Summary

Autism Spectrum Disorder (ASD) is the most serious of the neurodevelopmental disorders. People with autism have difficulty functioning in 3 core areas of development: social interaction, verbal and nonverbal communication, and have restricted patterns of behaviour, interests, and activities. Early identification of autism allows for the possibility of early intervention and the best outcome for the child and parents. Intervention provided before age 3 when the brain is most malleable has a much greater impact than intervention provided after age 5, and this is consistent with early intervention research with other populations.

While screening tools such as the Checklist for Autism in Toddlers (CHAT) and the modified Checklist for Autism in Toddlers (M-CHAT) can identify children at risk of a developmental disorder such as autism at 18 months, The Task Force Report on Autism (Ireland) 2001 found that that by the time their children reached four years of age, 56% of parents had not yet been provided with a clear diagnosis. This report also found that levels of training and awareness of early indicators of autism among health professionals was low. This suggests that the process of communicating research to practice in relation to early identification of autism is not operating effectively and efficiently in Ireland.

In order to address this gap this exploratory study looked at how ICT was being used in Ireland and abroad to support the process of getting research findings to clinical practice. The study found that there are two levels of disseminating research to practice. Firstly through the Internet using website technology and secondly through

the more sophisticated process of Clinical Decision Support Systems which embed best practice guidelines and are updated regularly as new evidence becomes available.

Recommendations were made to adopt both of these technologies to support early identification of autism in Ireland. The first was a recommendation for a website to be incorporated into a health information portal which is being developed by the health service executive (HSE) to address health information needs for the public and health professional alike. This website would provide access to information for parents and child health professionals on the early indicators of autism and also screening tools for autism for professional use.

The second proposal is for the development of an e-CHR, which would build on the current structures in place for children's early developmental assessments. This e-CHR would incorporate best practice guidelines for evidence based developmental assessments and would incorporate a decision support tool for the early identification of developmental disorders including autism.

List of Abbreviations:

Abbreviation	Description
ABA	Applied Behavioural Analysis
AIM	Artificial Intelligence in Medicine
AMOs	Area Medical Officers
ASD	Autism Spectrum Disorder
CDSS	Clinical Decision Support Systems
CHAT	Checklist for Autism in Toddlers
DLDs	Developmental Language Disorders
DSM IV	The Diagnostic and Statistical Manual of Mental Disorders
DSS	Decision Support System
DST	Dynamic Systems Theory
e-CHR	Electronic Child Health Record
EHR	Electronic Health Record
ERHA	Eastern Regional Health Authority
GP	General (Medical) Practionioner
GPIT	National General Practitioners Information Technology Group www.gpit.ie
HIQA	The Health Information Quality Authority
HSE	Health Services Executive
ICD 10	International Statistical Classification of Diseases and Related Health Problems, 10th Revision
ICGP	Irish College of General Practitioners
ICT	Information and Communication Technology
M-CHAT	Modified Checklist for Autism in Toddlers
NAS	National Autism Society
NMIC	National Medicines Information Centre
PHNs	Public Health Nurses
PHR	Public Health Record
PSI	Psychological Society of Ireland

TRIP	Turning Research into Practice
WHO	World Health Organisation
WWW	World Wide Web

CONTENTS:

1. Introduction

The importance of early identification of Autism Spectrum Disorder (ASD) is that it allows for the possibility of early intervention and the optimal outcome for the parent and child. Research in developmental psychology has demonstrated that a disorder becomes more pronounced as development progresses and symptoms become more pervasive or intensify with age (Baranek et al 1999) and therefore detecting symptoms at an early age is a critical precursor to early identification and intervention. In addition, intervention in the early years coincides with the most 'plastic' period of brain development and appropriate interventions at this stage may compensate for developmental abnormality (Grossman et al 2003).

Muller (2003) cites supporting evidence, which demonstrates that the developing brain is subject to numerous interacting factors, both genetic and environmental, and these combine to determine the outcome in both normal and abnormal development. Thus, evidence supports the importance of early identification for developmental disorders in that it provides for the possibility of compensatory interventions when the brain is most malleable in early development.

While evidence suggests the benefits of early identification and intervention, the structures to support this in Ireland are not yet evident. The Task Force Report on Autism (Ireland) 2001 found that by the time their children reached four years of age, 56% of parents had not yet been provided with a clear diagnosis. This was despite 87% of parents expressing concern about developmental delay at a very early age

(Murray ERHA in Autism report 2001) and despite convincing evidence that it is a neurodevelopmental disorder of prenatal origin (Muller 2003).

1.1   The research to practice link

The Task Force report (2001) also found that levels of training and awareness of autism among health professionals was low, despite the availability of screening tools and substantial research findings in this area. This suggests that the process of communicating research to practice in relation to early indicators of autism is not operating effectively and efficiently. When a sample of Irish GPs were asked if they were satisfied with the process of communicating research to practice, 47% said they were not (Smyth 2004). When asked if a screening tool such as the checklist for autism in toddlers (CHAT) would be useful for their practice, 81% said yes.

In order for ASD to be identified at an early age it is important that health professionals who carry out early developmental assessments with infants are kept up to date with research findings relevant to their practice. It is also important that information about the early indicators of Autism is available to parents who have a concern about their child's development. This study will explore what structures are currently in place to provide training and information for health care professionals on the early indicators of autism. In addition it will explore what support and information is currently available to parents who may have a concern about their child's development.

Traditionally, professionals who carry out developmental assessments such as Public Health Nurses (PHNs), Area Medical Officers (AMOs) and General Practitioners

2

(GPs) come from a medical background. However, as there are no biological markers for ASD to date, identification and diagnosis is made on the basis of a combination of communication and behavioural indicators such as language delay, deficits in social skills and obsessive or repetitive behaviours, and this would not fall into the traditional domain of medicine. Research carried out in the UK by Shah (2001) on what medical students know about autism, found that medical training in autism may need to be considerably improved if early recognition of this disorder is to be identified. While evidence from some medical research suggests there may be co-occurring physical symptoms in autism such as iron deficiency (Latif et al 2002), gastrointestinal problems, (Horvath et al 1999); (Horvath & Perman 2002), and head circumference in early development (Courchesne et al 2003); (Lawrence 2003); (Frith and Hill 2003), this research is still exploratory.

The field of psychology conducts research in behaviour development, including the behaviours which characterise ASD, and the processes underlying abnormal development (Charman 2003). However, it is child health practitioners who are best placed to identify early indicators of autism as they carry out routine developmental assessments on infants. This suggests that making behavioural research findings in the field of psychology available to medical practitioners who carry out developmental assessments of infants, could support the early identification of autism. Disseminating research findings to practice can be a lengthy process and according to Goldstein et al (2004) an average of about 17 years is required for new knowledge generated by randomised control trials to be incorporated into practice. This suggests that there may be barriers to the process of getting research findings to practice for medical practitioners wishing to keep up to date with current research findings. In addition, it

is likely that disseminating research findings from one field to another, in this instance from the field of psychology to the field of medicine, may also prolong this process.

1.2   The potential of ICT to support early identification of Autism

In order to identify what potential ICT has to support the early identification of Autism, this study will explore two approaches used in the field of informatics to disseminate research to practice: firstly through the provision of electronic databases and journals and secondly through the use of Clinical Decision Support Systems (CDSS) which incorporate research evidence, and provide clinicians with patient specific assessments and recommendations to aid them in their decision making (Kawamoto et al 2005). These decision support tools help to overcome the otherwise impossible task facing health care professionals of keeping up to date with the ever increasing amount of research evidence on the many illnesses and disorders they encounter. In addition these tools distil as well as disseminate research and can be updated to incorporate new research as it becomes available, as well as enabling the integration of current medical knowledge with detailed knowledge of the individual patient (Weed 1997).

The primary objective of this study is to investigate what contribution information technology can make to early identification of Autism in Ireland and two main aspects are considered:

    1. How research findings can be communicated to health care practitioners effectively and efficiently.

2. How general practitioner, area medical officer and public health nurse practice in Ireland can be supported by information technology to facilitate early identification of autism.

The study will investigate the first of these by examining

- i) How information technology is used internationally to communicate research to practice in the early identification of autism.

- ii) How research is communicated to practitioners in Ireland.

The study will investigate the second aspect outlined above by examining

- iii) What structures are in place in Ireland to support the early identification of autism

- iv) How information technology is being used, or has the potential to be used to support clinical practice in Ireland.

This chapter has provided an introduction to the importance of early identification of autism. It has identified the problem of communicating research to practice as a potential barrier to this process and has described two approaches which are enabled by ICT to disseminate research to practice.

Chapter two will provide the background to this study by describing autism spectrum disorder (ASD) and some theoretical approaches which seek to explain the different factors influencing the process of early development. It will then describe current research evidence on early indictors of autism, what screening tools are currently available, which incorporate this evidence, and when these tools are most suitable for use.

Chapter three will describe what structures are in place in Ireland to support the early identification of autism (iii). Chapter four will address the remaining three objectives for this study as follows:

(ii) How is medical research communicated to practice in Ireland?

(iv)How is information technology being used, or has the potential to be used to support clinical practice in Ireland?

(1) How is information technology being used internationally to communicate research to practice in the early identification of autism?

Chapter five will then analyse the findings from chapters three and four and drawing on conclusions from these findings recommendations will be made concerning the use of information technology to communicate research to practice to support the early identification of autism in Ireland. The study will then conclude with a brief summary of this report describing the main findings.

2. Early Identification of Autism

2.1 Introduction to Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is the most serious of the neurodevelopmental disorders. Early identification allows for the possibility of early intervention and the best outcome for the child and parents. Research in developmental psychology has demonstrated that any developmental abnormality is potentially compensated by developmental plasticity especially in the first years of life when the brain is most malleable (Muller 2003).

The three defining features of ASD are: impaired reciprocal social interaction; impaired communication skills; and restricted, repetitive and stereotyped patterns of behaviours, activities and interests. ASD is three to four times more common in boys than girls (DSM-IV-TR in Siklos & Kerns 2006). While prevalence rates are still being established in Ireland following the Autism Report, current estimates suggest prevalence rates of 1 in 166 (Mesibov 2006). However prevalence rates vary (Siklos & Kerns 2006). The spectrum nature of the disorder, with symptoms variation from mild to severe, and co-morbidity with other conditions such as learning disability, may explain the differences in prevalence rates. It is the fastest growing developmental disorder in the United States. This year more children will be diagnosed with autism than AIDS, diabetes and cancer combined (Krieger Institute 2006) and these prevalence figures are approximately treble the rates of childhood obesity in the US (Time Magazine 2006).

There is some debate concerning the reasons for the significant increase in the prevalence of autism in recent years. One explanation put forward is the advances that have been made in understanding the nature of this disorder, and also the development of screening and diagnostic tools for autism. It is suggested that there has been a corresponding drop in the rates of mental retardation, due to the reclassification of this disorder, but incidence studies have also reported an increase in estimates over time (Williams and Brayne 2006). However, there is broad agreement concerning the benefits of early identification and intervention (Mesibov 2006; Siklos & Kerns 2006).

The two key areas of difficulty for children with autism are social interaction and communication. Research evidence demonstrating how these skills are acquired from early infancy will now be described, as well as a brief description of repetitive stereotyped behaviours, the third diagnostic criteria for autism. Findings which show that acquiring social and communication skills is an iterative process in early development, progressing gradually from the comparatively simple to increasing complexity over time, will now be considered to demonstrate why early diagnosis and early intervention supports the best outcome for these children, and their parents.

Social deficits such as impaired ability in pretend play and imitation are generally considered the most prominent characteristic of very young children with autism (Swinkels et al 2006) and research evidence suggests that these skills underpin the development of language. The acquisition of language is a complex as well as a fascinating process. Many disciplines collaborate to increase our understanding of this fundamental human skill (ref). Chapman (2000) gives a comprehensive account of the evidence from the 'nature' and 'nurture' sides of the debate and provides substantial

evidence for adopting an 'interactionist' perspective, that is, that both nature and the environment play an important role in language development. As intervention is mostly concerned with the role of the environment in supporting language development, it is evidence from this area that will now be discussed. Research into the *process* of language acquisition demonstrates that the key processes underlying language development begin from the moment of birth and that babies even listen to the voice of their mother in the last few months of pregnancy (De Villiers 2000). De Villiers (2000) describes the iterative process involved in the infants development of social and communication skills over time: 'Human infants are acutely attuned to the human voice and prefer it above all other sounds'. They are also attentive to the human face, particularly the eyes, which they stare at even more if the face is talking. This very early attention to the mothers' face and eyes progresses until at around 4 months, babies are smiling at caregivers and engaging with them in a cooing noise that is irresistible to most parents. The caregiver typically responds by echoing these sounds and thus creates an elaborate exchange that can last a number of minutes.

At a point between four and ten months, more 'speech like' syllables are produced by the infant described as 'canonical babbling'. At around six to eight months, the vocalisation range grows dramatically, and babies appear to practice the sounds they can make with their mouths for hours at a time in this period. This range narrows by ten to twelve months, and babbling begins to take on the characteristics of the language of their culture. Babbling now consists of reduplicated sounds like 'mamama', 'dadada', and 'bababa' explaining why most of the world's languages use some form of these syllables as a name for parents. Between nine and fifteen months babies utter their first words and this seems to depend on the precocity of the child and the parent's

enthusiasm in noticing. Very shortly after, these words are then used to communicate

seeking a caregiver's attention or to demand an object/toy and the words are used

persistently until the desired response is forthcoming.

This pattern continues with several months of slow growth, followed by an explosion

of words, commonly referred to as 'word spurt'. This occurs alongside a developing

interest in what things are called along the lines of 'what's that'? The child's

vocabulary increases rapidly at an approximate rate of nine words a day from ages two

to eighteen years Studies with other languages have indicated that this pattern of

language development is also evident across cultures. Of interest also in relation to the

pattern of language development is that the nature of the child's first fifty words are

also quite similar across cultures.

Recent research has also lent support to the importance of the language spoken to

children from birth onward, and the infant's sensitivity to language even while still in

utero (Chapman 2000). Another factor influencing language development is the

infant's exposure to language. A longitudinal study of parent- child interaction cited

the significant effects of language input on the child's subsequent development of

language (Hart and Risley 1992). Wide ranging differences were found in the amount

of talk addressed to children, which ranged from 56 to 793 utterances per hour in the

12-18 month age period, and was also associated with the amount of time that parents

spent in interaction with their children. These hourly differences in language exposure

translate over a day to a difference of 700 utterances compared with 11,000, and

evidence suggests that this difference predicts child language outcomes at three years

and nine years. Other studies with parents' use of language with their infants and

toddlers have identified a conversational speech style that is associated with more rapid language development (in Chapman 2000). Researchers also agree that the most effective language learning environment is in social and interactive exchanges with an accomplished talker, who may be another child. Based on comprehensive multi-disciplinary research, Chapman (2000) offers evidence which lends support to the effects of enriched environments on the developing brain and in turn, the subsequent effects on behaviour. While Chapman (2000) also cites wide ranging studies demonstrating the effects of genetic inheritance, the evidence concerning the effects of early experience, lending support to the benefits of early intervention is of most interest here.

While this description focuses on the process of normal development of language, evidence from video recordings of children's first birthday's and parent's retrospective report indicate that children who are subsequently diagnosed with autism differ in social behaviour from a very early age. These children have problems with eye contact, orienting to their name and non-verbal communication such as pointing and showing at a very early age and these skills underpin language development. This will be discussed further in section 2 on the early indicators of autism.

2.2   Repetitive Stereotyped Behaviours

Repetitive, restricted and stereotyped patterns of behaviour, interests and activities, is the third of the three criteria used to diagnose Autism in DSM IV (The Diagnostic and Statistical Manual of Mental Disorders) and ICD 10 (International Statistical Classification of Diseases and Related Health Problems, 10th Revision).

Repetitive behaviours, however, are not exclusive to autism and can be displayed by normally developing children also. They serve functions such as enhanced learning through repetition and lowering anxiety through predictability of routine (O'Brien and Pearson 2006; Honey et al 2006). In normally developing children, these behaviours decrease significantly around the age of four, although some persist such as nail biting, pacing and keenly pursued hobbies but these behaviours are not unusual or considered abnormal. However, the amount and frequency of repetitive behaviours among children with autism is significantly higher than normally developing children. Examples of these behaviours include body rocking, hand flapping, head banging and spinning. These particular types of stereotypical, repetitive behaviours tend to manifest later than social/communication behaviour difficulties in autism from around age two onwards (O'Brien and Pearson 2006; Stone et al 2003;Young et al 2003). These behaviours are a relatively neglected area of study in autism.

2.3   Summary

The key features of ASD are poor social skills, impaired development of language skills and repetitive behaviour patterns. ASD is becoming increasingly more prevalent and is more common in boys than girls. Given that the symptoms of ASD can become increasingly complex over time, early identification of the disorder is essential to ensure that the appropriate interventions can be planned and delivered. Understanding the developmental process of language and social skills provides an opportunity for early intervention when this pattern deviates significantly in children with autism and other developmental disorders. Section 2.4 will now look at developmental theory which provides a basis for understanding early childhood development and why early intervention at an early stage of a child's development can lead to better outcomes.

2.4   Developmental theory

The process of language acquisition is a good example of the complexity and interactivity of the process of human development, especially in the first three years of life when the brain is most malleable (Muller 2003). Dynamic systems theory is a new approach to understanding the process of development in psychology, science and many other related disciplines (Gaussen 2000). Some examples of the application of this theory to human development and to development in the sciences will now be described, to illustrate current thinking on early development, and the many factors which combine to influence this complex process. In addition, the influence of early experience on the developing brain, and the importance of early identification and intervention in the event of developmental abnormality will also be considered.

2.5   Dynamic Systems Theory

Dynamic systems theory (DST) proposes a model which offers a new perspective on the nature of causality and change in human development. This theory replaces previous linear, maturational theories and is a recent revolution in the scientific theory of change in complex processes. In essence, a dynamic system is any system whose behaviour at one point in time, depends in some way on its state at an earlier point in time, and which emerges from the interplay of many factors over time. This revolution in the understanding of processes of change in complex physical and biological systems has found application to psychological development and has implications for atypical development and psychopathology (Chapman 2000). It is now proposed that many factors acting over time may be involved in causality in human development, and change is seen as an emergent property of the system whereby a small change at one level may produce large emergent effects on the system overall (van Geert 1997 in

13

Gaussen 2001). This view is supported by changing perspectives on genetic

determinism supported by evidence from molecular biology research (Rose 1997 in

Gaussen 2000). This research demonstrates that there is no single locus of a gene, no

'thing' identifiable as a gene, but a series of interlocking protein chains, which may be

spatially separated, and which can only act in concert with the rest of cell chemistry.

In recent biological models, genes, cells, the whole body and the environment are now

viewed as being inseparably linked and do not make separate, individual contributions

to development. (Dent Read & Zukow – Goldring, 1997; Richardson 1998 in Gaussen

2000).

2.5.1   Dynamic Systems Theory and Brain development

Findings in developmental neurobiology concerned with dynamic processes involved

in brain development, lend further support to DST. Schore (1994,1996,1997 in

Gaussen 2000) has documented the manner in which the neurochemistry and

architecture of the developing brain is changed by intrinsic and extrinsic factors

present in the caregiving environment. He proposes a model in which infant-caregiver

relationships can affect the brain pathways concerned with the development of affect

regulation and personality. His research shows how the organisation of the orbital area

of the prefrontal cortex is intimately associated with the limbic areas of the brain which

governs emotional processes. This research demonstrates how the growth of neural

pathways, and the responsiveness and self-regulation of this system within the brain,

may be altered by early experiences in interactions with caregivers. His findings

showed how early interactions can trigger positive emotion in the infant through the

biochemistry of endogenous opiates which are produced in response to caregiver

stimuli, such as the emotional interchanges involved in early proto-conversations and reciprocal smiling.

Gaussen (2000) summarises this research and concludes that the dynamic systems of the early infant caregiver transactions can therefore be seen as building the actual neurological structures which underlie human function and subsequently affects the individual's later interpersonal interactions. DST is essentially a mathematical theory, which is now being applied to a wide range of physical, chemical and biological systems. It has already been successfully applied to a wide range of complex natural phenomena in the physical sciences, including biology, in studies of complex living organisms and eco systems. Its application to developmental biology and the neurosciences is now producing testable scientific hypotheses, which are beginning to produce results in the literature, as well as models for clinical interventions.

2.5.2   Dynamic Systems Theory and the role of experience in brain development

Grossman et al (2003) also describe the effects of *experience* on brain development using DST. They use the word e*xperience* to describe non-genetic factors such as interactions between an organism and its environment. They describe the research findings of the last thirty five years which has shown an increased appreciation for the roles that experience can play both in moulding brain function in development and in continuing to sculpt the brain throughout adulthood. A consistent finding in these studies over the years is that experience has its effects via activation of genes and modification of their function. Visual experience, of the infant for example, alters how genes are expressed in the developing visual system and this results in physiological and anatomical changes in brain organization. They also describe how the effects of

15

visual experience involve proteins that contribute to cell structure, and that this is a mechanism through which experience may have lasting effects on neural function. They make reference to several theories which suggest that early adverse experience can have dramatic effects on the developing nervous system.

2.5.3   Dynamic systems theory and increasing complexity

Roger Brown (1973 in Chapman 2000) adds another important developmental dimension to dynamic systems theory, describing the process as one of cumulative complexity, where the 'new' emerges out of 'old' patterns; that which required both X and Y would be learned later than either X or Y developmentally. Chapman (2000) puts this in context by describing two generalisations which have emerged from twenty five years of research in to the nature of children's language learning; Firstly, language acquisition follows a course in which new meanings and communicative functions are first expressed by old means or forms, of behaviour – whether gesture, vocalisation, word, or sentence structure. Relating this to Roger Browns theory, X and Y could refer to gesture and vocalisation as developing *separately*, and then X and Y combine *together* to produce the first word, and then as words production increases, they combine to make sentences, and so on.

Secondly, new forms of communicative behaviour typically emerge to express meanings and communicative intents already in the child's repertoire. This suggests that infants 'take in' language before they 'express' it. These findings also support the strong advice to parents that they respond to children's communicative attempts and appropriate form will follow. This evidence also supports an interactionist approach whereby new motor, cognitive and social learning serve as precursors to the emergence

of particular linguistic forms; and that acquisition of linguistic forms in turn can lead to subsequent development in other spheres (Chapman 2000).

DST provides some important insights into early childhood development which are relevant to this study. In particular, it sheds light on the development of the brain and points to the importance of early experiences of interactions between a child and a caregiver. DST shows that such early interactions can have a potential impact on subsequent development and an individual's later interpersonal interactions. Section 2.6 will now present some of research evidence in relation to early indicators of autism'.

2.6   Research findings on early indicators of autism

It is now generally accepted that the first manifestations of autism occur in early infancy (Receveur et al 2006) and many of the impairments observed in pre-school children are behaviours that are developmentally online by the end of the first year of life. Researchers have used innovative methods such as analysis of home videos taken during the first year of life, and compared the videos of children who developed normally to those who were subsequently diagnosed with autism (Osterling et al 2002, Adrien et al 2001, Werner et al 2000, Baranek 1999, Teitelbaum et al 1998) While these studies have been small, and some have still to be replicated, similar coding methods have been used in some, and there is a consistency in findings in that they can all be categorised under abnormalities in social relations and communication. One study by Teitelbaum et al (1998) found that motor deficits could be identified in the first year of life.

These indicators include poor social interaction such as failure to respond to their name, absence of social smiles, less looking at others, aversion to social touch, unstable attention, and poor imitation behaviour, the latter which has been shown in studies to be always impaired in toddlers with autism (Receveur 2000). Motor deficits include abnormal development in motor skills in lying, righting, sitting, crawling and walking (Teitelbaum et al 2003). Across studies, several social behaviours have been found to be absent or significantly limited in children with early onset autism during the first *two* years of life. Some are also evident in the first year of life but may be more prevalent by two years and include joint attention (sharing interest with another), looking at the faces of others, interest in other children, simple pretend play activities, sharing enjoyment with others, and responding to their name (Baron-Cohen et al 1996; Lord; Osterling and Dawson 1994, in Receveur 2000). Stereotyped behaviours, a need for sameness and stereotyped language may not emerge until later in development (Cox et al 1999; Lord 1995; Dahlgreen and Gilberg 1989).

Gray & Tonge (2001) suggest that that 75-88 percent of children with ASD show some of the defining social and communication deficits before two years of age and that a clinical diagnosis of autism at age 2 is reliable and stable (Moore & Goodson 2003; Lord et al 2006; Turner et al 2006). The earliest diagnosis of Autism Spectrum Disorder (ASD) is around 2 years of age but the typical age for diagnosis is 4-5 years (Charman & Baird 2002). This is despite the findings of Howlin and Moore (1997) that in the majority of instances there are indicators of ASD in infancy and many parents are seriously concerned about their child's development in the first year of life. Autism spectrum disorders are being diagnosed at least two years after parents suspect their child has developmental problems and this delay is preventing some children

18

from receiving the benefits of early intervention (Gray and Tonge 2001 in Mesibov 2006).

2.7   Preliminary research findings on *biological* indicators.

Research on biological indicators for autism has identified a number of factors which may be of significance for sub groups within the autism population. Two will be considered here: iron deficiency and head circumference.

Iron deficiency

A study conducted by Latif et al (2002) found that 52 % of children with autism (under four years of age) were iron deficient. This was compared to a group of children with Aspergers Syndrome where only 13% were iron deficient. This deficiency can impair cognition and affect and is associated with developmental slowing in infants and mood changes and poor concentration in children, and this could further compromise the communication and behavioral impairments of children with autism.

Head circumference

These include differences in head circumference as mentioned above (Lawrence 2003) whereby children with autism have a *lower* head circumference at birth (Lawrence, 2003), but by the time they reached two to three years, these children had a head circumference that was *greater* than that of normally developing children. It was also found that the children who had the largest head circumference by the end of the first year had the most abnormal overgrowth of several important brain structures including

the cerebral cortex. This area of the brain has a role in basic functions as well as higher functions such as social cognition, language, memory and attention.

This research on early biological indicators of autism are still at an early stage but may support the early identification process in the future.

As research is now beginning to focus on the *early* indicators of autism, the findings are increasing knowledge of the more subtle indicators of developmental disorders which parents and child health professionals can be aware of, once they have easy access to this information. Early identification when the brain is most malleable and the behaviours more subtle will enhance the developmental outcomes for these children and their parents. Section 2.8 will now describe some of the more promising screening tools for early identification of autism and what are their strengths and limitations.

2.8   Screening tools for autism

Diagnosis of Autism Spectrum Disorder is currently made on the basis of *behaviours,* which is primarily the domain of the discipline of psychology as there are as yet, no biological indicators for autism which affect all children. Behaviours require observation, whereas medicine typically relies on physical symptoms. Children with autism tend to look fine physically, and it is only in interaction with the child that their difficulties become apparent. However, this takes time, which a busy practitioner does not have, and therefore the practitioner needs to take careful account of any concern expressed by the parent. Research has consistently shown that when a parent has a concern about their child's development, they are almost always right (Autism report

20

2001). The advantages of screening tools for Autism, such as the CHAT and M-CHAT (Appendix 1) are that they include information on parent observation, they are quick for the practitioner to administer and they cover key indicators identified by research evidence as meriting further investigation. Both of these screening tools will be described now as well as the potential of the 'head tilt test' and 'red flags' for autism.

2.8.1   Checklist for Autism in Toddlers (CHAT)

Mesibov et al (2006) have reviewed the screening tools currently available for autism and they concluded that while some of these tools such as the checklist for autism in toddlers (CHAT) and the modified checklist for autism in toddlers (M-CHAT) are not suitable for population screening, i.e. screening *every* child in the population. They would be suitable for secondary screening, such as when a parent or health care professional has a concern about a child's development. The Checklist for Autism in Toddlers (CHAT) is a short questionnaire which is filled out by the parents and a primary health care worker at the 18 month developmental check-up. It aims to identify children who are risk for social-communication disorders such as autism.

This screening tool consists of two sections: the first nine items are questions asked to the parents, and the last five items are observations made by the primary health care worker. The key items look at behaviours which, if absent at 18 months, put a child at risk for a social-communication disorder. These behaviours are (a) joint attention, including pointing to show and gaze-monitoring (eg looking to where a parent is pointing), and (b) pretend play (eg pretending to pour tea from a toy teapot).

The CHAT is very easy to score. There are five key items: A5 (pretend play), A7 (protodeclarative pointing), Bii (following a point), Biii (pretending) and Biv (producing a point). If a child fails all five key items, they have a high risk of developing autism. Children who fail items A7 and Biv have a medium risk of developing autism. It is recommended that any child who fails the CHAT should be re-screened approximately one month later. As with any screening instrument, a second CHAT is advisable so that those children who are just slightly delayed are given time to catch up and also to focus efforts on children who are failing consistently. Any child who fails the CHAT for a second time should be referred to a specialist clinic for diagnosis since the CHAT is not a diagnostic tool.

The strengths of the CHAT are that it has been validated on a large population of 18 month old children in the UK (Baird et al 2000) and this study demonstrated high specificity for the CHAT (.99) and positive predictive value, which means that children who tested positive with this screening tool were highly likely to be diagnosed with autism subsequently. However, the limitation of the CHAT is its low sensitivity (.20), which means that it missed close to 80% percent of children who were subsequently diagnosed with Autism. However, this sensitivity improves when it is used for children whose parents express a concern, rather than a *population* screening tool where all children are screened as was the case in this study.

Despite this limitation, the use of the CHAT has also been instrumental in increasing *awareness* of the early indicators of Autism. In one study where this screening tool was used, the subsequent familiarity with the CHAT screening tool increased

knowledge and understanding of autism among health care practitioners in the districts

where the screen was used. This in turn resulted in earlier referral and diagnosis of

children who had autism but who were not identified by the screen, and contributed to

the existing surveillance methods (Baird et al 2001). The National Autism Plan for

children in the UK (Le Couteur et al 2003) also recommended that autism can be

detected through increased awareness amongst parents and health professionals, and

that tests designed as screening tests may be valuable if used as secondary screens

where there are known developmental problems.

2.8.2   Modified checklist for Autism in Toddlers (M-CHAT)

The M-CHAT is a screening tool for slightly older children between the ages of 18 and

30 months and was developed in order to identify those children whose symptoms

become apparent between these time periods. It is a questionnaire which is built on the

CHAT items but is expanded to a 23 item yes/no questionnaire to be given to parents

(Eaves et al 2006). The M-CHAT has only been used as a secondary screening tool to

date, but its performance was encouraging in this slightly older age group 18-30

months, with results indicating high sensitivity and specificity (0.97 and 0.95). The six

most sensitive items have been identified also, any two of which place the child in the

'at risk' category.

Evidence supports the important role parents play in the early identification of autism

(Autism Report 2001; Wimpory et al 2000 in Swinkels et al 2006 and there is evidence

that the use of screening instruments in combination with asking parents about their

concerns improves the efficiency of a screening tool (Baird 2001). It combines the

observations of parents with the developmental knowledge of the professional which

can then be followed up by screening with specific tests. Parents are in the unique position of being able to observe their children's behaviour across contexts and time and this knowledge has been incorporated into parent questionnaires to support early diagnosis (Stone et al 2003;) and other screening tools which have not yet been fully validated (Eaves et al 2006;). When parents were asked retrospectively about their child's behaviour in the first two years of life, their responses matched behaviours characteristic for autism (Wimpory et al 2000 in Swinkels 2006). As evidence has established the validity of parent information, some screening tools such as the M-CHAT have been designed to be filled out by parents prior to their appointment with the health care professional.

Like the CHAT, the M-CHAT has successfully identified children who were subsequently diagnosed with autism, but unlike the CHAT, it missed very few children who were subsequently diagnosed with autism. However, this tool has not yet been validated for primary screening, which it was designed for, whereby it could be used as a routine screening tool rather than when a concern has arisen about a child's development. However, its use as a secondary screening tool looks very promising as it incorporates parental report, and would be very useful where a parent expresses concern about their child, or where a professional has concern about a child's development. While there are a number of other screening tools developed for screening for autism in the age group 0 – 5 years, they have not yet been validated in the general population.

2.8.3   The 'head tilt test'

Another *potential* screening tool is the 'head tilt test', which is a very simple test designed to test the reflex that young babies have to keep their head vertical. [New

sentence] It has been proposed by Teitelbaum et al (2004) that this test may be diagnostic for infants at risk of developmental disorders. A pilot study is being conducted in the US with baby siblings of children who already have an autism diagnosis. The aim of this pilot study is to establish whether motor tone and the 'head tilt test', either alone or in combination with other measures such as changes in head circumference, may be an early biological marker for a subgroup of infants at risk of developing autism. The benefits of this test are that it is quick, easy and a very early indicator, and can be conducted at no extra cost for the health professional or parent

2.8.4   Red Flags for autism

The Child Neurology Society and American Academy of Neurology developed a list of 'red flags' for autism for children under two years (Filipek et al, 2000).These 'red flags' were drawn from over 2,500 relevant scientific research articles intended to improve the rate of early identification and diagnosis of, and therefore early intervention for, autism (Appendix 2 for full list). The authors recommend that the following 'red flags' may indicate a child is at risk for atypical development, and is in need of immediate evaluation.

- No big smiles or other warm, joyful expressions by six months or thereafter
- No back-and-forth sharing of sounds, smiles, or other facial expressions by nine months or thereafter
- No babbling by 12 months
- No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months
- No words by 16 months

- No two-word meaningful phrases (without imitating or repeating) by 24 months

- Any loss of speech or babbling or social skills at any age

Screening for early indicators of autism provide an opportunity for early intervention. While screening tools such as the CHAT and M-CHAT are not validated for population screening, they are suitable for use when a parent or child health professional has a concern about a child's development. In addition, the use of these tools enables the child health professional to become more familiar with the early indicators of developmental disorders such as autism. The M-CHAT, which builds on the original CHAT, is already showing better rates of early identification compared to the CHAT. This demonstrates the importance of child health professionals having up to date knowledge and ready access to these tools as they become available.

2.9   Summary

This chapter has described the early indicators of autism and why early intervention before three years of age provides for the best outcomes for children at risk of developing this disorder. Dynamic systems theory supports the importance of early identification and explains how a small change early in development can have significant effects on subsequent development. Language and social development can also be understood as a developmental 'system', which increases in complexity as development progresses and follows a similar developmental pattern across cultures. Language problems are almost always the presenting concern of parents whose children are subsequently given a diagnosis of autism.

Screening tools such as the CHAT and M-CHAT can identify early indicators of autism at 18 months and are most effective when used for secondary screening, i.e. when a parent or child health professional has a concern about a child's development. Research evidence indicates that when a parent has a concern about their child's early development their concerns are well founded.

2.10 Conclusion

Research evidence from chapter two supports the benefits of early identification of developmental disorders such as autism. Screening tools such as the CHAT and M-CHAT are easy and quick to use for child health professionals and are free to download from the Internet. Chapter three will now look at the structures in place in Ireland to support early identification of autism.

3. Autism services in Ireland

This chapter addresses objective one of the research as listed in chapter one as follows: What structures are in place in Ireland to support the early identification of autism spectrum disorder?

To address this objective, this chapter will describe the opportunities that exist for early identification of autism within existing health service structures. It will then identify where there is potential for enhancing the process of early identification of autism within these structures and will indicate what are likely the obstacles to best practice currently.

3.1   Introduction

The autism report 2001 pointed to the low levels of awareness of early indicators of autism among health care professionals at that time (Autism report 2001). In order for early identification of autism to happen as quickly as possible, it is necessary that relevant health care professionals have access to training and up to date research information on potential indicators for concern. In addition it is important that parents have access to reliable information and support when they first have a concern about their child's early development. As this report indicated, many parents were concerned about their child's development in the first year of life, but the typical age for diagnosis at that time was 5 years of age. The lost opportunity for early intervention that this presents has been documented in the previous chapter and diagnosis at age two has been shown to be reliable and stable (Turner et al 2006).

This chapter will now describe briefly what would be best practice in terms of 'links in the chain' that would need to be in place from the point of the parent first having a concern about their child's development to accessing assessment, diagnosis and intervention services to facilitate the best outcome for the parent and child. This will be described taking account of the structures that currently exist in the HSE.

Based on research findings from studies with parents, and information from a number of health professionals interviewed for this and a previous related study, this chapter will then describe what is *actually* happening in terms of early identification of children at risk of autism in Ireland today. Current policy and relevant legislation will then be discussed in brief to gain an understanding of the context of autism within the health service today.

3.2   Links in the chain for early identification of autism

 There is currently provision for regular monitoring of children's development during the crucial developmental period 0-3 years. As described in chapter two, there is substantial research evidence supporting patterns in children's early development and any substantial deviation from this pattern could alert professionals and parents alike. Once professionals and parents have access to this information, screening and diagnosis could proceed rapidly, once there is a referral system in place, and the opportunity is then available for early intervention. Ideally, all health professionals who carry out these assessments would have received training about autism and other developmental disorders, and have access to current research about the types of developmental disorders they are likely to encounter and what indicators to look out

for. It would be important that this information would be easily accessible and not time consuming to access. They would also have knowledge about, as well as ready access to, screening tools which are easy to use and don't take too long to conduct, when they have a concern about a child's development.

As identified in chapter two, many parents have concerns about their child's development in the first year of life but there is a long gap between first concerns and eventual diagnosis. Once a parent has any concern, they should also have immediate access to information, and support from a health professional who has experience and up to date knowledge about developmental disorders, and information about the referral process. While the parent is awaiting assessment for their child, they could be provided with whatever guidelines are available from current research, which can help them support their child's development while they are awaiting intervention services, such as speech and language services and occupational therapy for example. The structures in place to support children's early development will now be discussed with reference to the process of developmental assessments and the Child Health Record**.**

3.2.1   Developmental Assessments

Within existing structures in the health service (HSE) it is planned that children have developmental assessments at regular intervals from birth to 3 ½ years, a time of rapid development for the infant. There is a statutory obligation to carry out the primary visit 48 hours after the mother is discharged from hospital. Under 'Best Health for Children' (2001) there is a core screening programme which encompasses 6 developmental checks at 48 hours post discharge, at 6 weeks, at 3 months, at between 7- 9 months, at 18-24 months and between 39- 42 months. Gross motor development,

fine motor development and vision, social development, play and communication

milestones are assessed during these checks and this information includes height,

weight, and head circumference, most of which have relevance to early indicators of

autism.

The health professionals who carry out these developmental assessments are public

health nurses (PHNs), general practitioners (GPs) and area medical officers (AMOs).

According to the Child health record a GP carries out the 6-8 week check, the PHN

carries out the primary visit, the 3 month, 18-24 month and the 3¼ to 3½ year

developmental assessment. The AMO carries out the 7-9month developmental

assessments. However, this may also vary from region to region depending on staff

availability and distribution.

3.2.2   The Child Health Record (CHR)

The results of children's developmental assessments are recorded in the Child Health

Record booklet called 'My Personal Health Record' (Appendix 3) which has 5

sections. One of these sections covers 'health and development checks' where

developmental data is recorded for each developmental assessment that the child has.

There are 3 copies of this assessment, one copy is stored electronically in the child

health office centrally in some regions of the HSE currently, the other is stored by the

Public Health Nurse locally and the third copy is kept by the parent.

What is actually happening

However, in previous research (Smyth 2004), and in the media in June this year (Irish

Times 2006) it was reported that these developmental assessments are not consistent

and in *some* areas of the health board, some of these assessments have been suspended. A representative of the Irish Medical Organisation (Irish Times June 2006) described waiting lists of up to 30,800 children for developmental assessments, some of whom have never had a developmental assessment. This report referred to the rapid growth of children during this period and that a delay in picking up and referring on a problem could have disastrous results. While this concerns all childhood illnesses, specific reference is made to developmental delay, where 'every month missed out on is vital. Early intervention by specialists can allow every child to reach his or her potential and offers parents the support they need in caring for their child.' This is despite the government's commitment to ensure that children would receive quality supports and services to promote all aspects of their development in the National Children's Strategy in 2001.

The importance of these assessments in relation to early intervention for autism is that they provide a record of the child's development in the key areas of social, communication and motor assessments, all areas of concern in developmental delay including autism. A PHN training professional explained that when these assessments are carried out regularly, PHNs or GPs will usually have developed a relationship with a parent and the parent is then also much more likely to express a concern to a PHN or GP who can then refer on to the appropriate services when necessary (Smyth 2004). Any potential problems can also be noted and followed up at each assessment if the problem persists.

However, in one region of the health board the percentages of these assessments which are successfully completed are very high in comparison to the Leinster area. In this

region, all information is stored electronically and they currently succeed in screening 90 per cent of children for all developmental checks, and 80% of those are within the recommended time periods for these developmental assessments. Two of the four regions of the HSE store all this developmental data electronically and the other two regions are in the process of doing this.

Data which may be relevant to early indicators of autism are recorded from the three month developmental assessment onwards. In addition very useful information is given to the parent describing what 'most babies can do' at this three month period, and they also relate to social and communication development. This is done for the following three checks also. At the 7-9 month check, there is a dedicated area for developmental data on the child health record in relation to movement, hearing and speech, and social play and behaviour and again supported by 'what most babies do now', which again covers language, and social response. In addition there is space for recording other checks carried out at this time, such as a full physical examination.

At the next check, the 18-24 month check, developmental assessments appear to be the only check done at this period. This is the period for which the CHAT screening tool was developed. While there is a lot of useful information provided for the parent in relation to this assessment, none of these CHAT items are included in the Child Health record. Further reading of this child health record however, revealed very useful guidelines for parents for supporting children's speech and language development in the 'health and safety section' of the child health record. For the 18 months-2 years period, it also indicates that children should be 'pointing' at this time.

3.2.3   The Child Health Record Review process

This current child health record was produced following a recent review in 2005. Prior to this, the child health record was reviewed annually in most of the eight local health areas prior to the current HSE restructuring process. When asked whether the use of screening tools for early indicators of autism had been considered in this review, a member of the review team indicated that the review groups don't have the people, money or the time to implement a screening programme to identify developmental problems at this point in time, and there is no national process currently.

This review team are currently evaluating a tool to screen for developmental problems called the PEDS, which is used from birth to eight years. This is then followed by screening with the M-CHAT, once the child reaches two years of age. There are ten questions which could be included for each of the time periods for developmental checks, and if found to have proven validity, they will be considered for inclusion in the Child Health Record. However, they are only at the beginning of this process and according to this review group member, it is not likely to happen for a few years at least. She also indicated that there is no advisory group for autism currently nor for the larger area of children's health.

3.2.4   Training for Health Care professionals on Autism

Public Health Nurses

Previous research (Smyth 2004) indicated that there is no specific training or lectures given in the area of autism spectrum disorder for public health nurses. A member of the PHR review group (2006) also indicated that the national training programme for PHNs does not cover training in the area of Autism. Training is given in the area of

child development and this focuses on normal development and what are the deviations from that. Research is communicated to practice through accessing Nursing journals, Medline and other Electronic Journals, as well as lectures and conferences on specific topics.

General Practitioners

In an interview with GP training professional (Smyth 2004) it was indicated that there is no specific training module on Autism as part of General Practitioner (GP) training. However, GPs may opt to go to seminars given by multidisciplinary teams on specific areas such as autism. This is not compulsory and it depends on the GPs area of interest. Prevalence rates of a particular disorder will affect how it is prioritised in training and prevalence rates for autism spectrum disorder are not yet available, but this data is currently being gathered. This GP stressed that communication and awareness are important if researchers in the field of ASD have a contribution to make to GP training and practice. He suggested that if a researcher can 'sell' their case in terms of prevalence and the importance of early diagnosis and intervention, and have the evidence to support that, then it would get the attention it deserves in GP training.

While the CHR indicates that the GP does just one of the developmental assessments at 6 weeks, they are nevertheless a very important link in the chain. They are likely to see a child when they have a temperature or any other illness in early development and the parent may take that opportunity to express a concern about a child's development when they have one.

Research is communicated to practice through accessing databases and journals such as Medline, IMJ, BMJ and many others. These are also accessible through two dedicated GP websites, Irish College of General Practitioners (ICGP) and National General Practice Information Technology group (GPIT) which provide access to a lot of information for GPs and this will be discussed later in section 4.2 under the topic of 'communicating research to practice'.

Area Medical Officers (AMOs)

AMOs are medical doctors and they also conduct developmental assessments with infants but attempts to make contact with this group were not successful. According to current information in the child Health Record, AMOs examines the infant at a developmental clinic at the 7-9 month assessment and participates in the school health and vaccination programmes. In addition they are responsible for the surveillance and control of infectious diseases.

It was indicated by one psychologist that there was a general lack of knowledge among GPs and professionals about autism. She referred to the autism report (2001) which had recommended the use of the CHAT screening tool at the 18-month developmental check, but this had not yet been implemented. This was also supported by a psychiatrist, also with expert knowledge in the field of autism, who recommended that all GPs and practitioners involved in early developmental assessments should use this tool. A clinical nurse specialist interviewed for this study (2006) indicated that the CHAT is being used in some child health clinics but it wouldn't be consistent. One psychologist indicated the importance of health professionals having the opportunity to

36

see behaviours typical of autism and he also indicated that there is a suitable video available.

3.2.5   Information for parents about the early indicators of autism

A recent study (Sovio Heron 2004) which compared experiences of parents of adolescents with autism in Ireland and Finland, found that many Irish parents had found it difficult to get a diagnosis which led to feelings of frustration especially among the parent's of young children, due to their knowledge of the importance of early intervention. Irish parents also expressed a need for a quicker process for receiving the diagnosis.

In addition, a leading psychiatrist in autism diagnosis in Ireland indicated that when parents finally get to him for a diagnosis, they had got a lot of their information from the Internet and public health professionals were not a typical source of information. When they finally received their diagnosis, the response from parents was often' if only I knew this two years ago'. However, he also indicated that the 'quality of the information' could be an issue when accessing the Internet for information in relation to autism.

However, there was also evidence of referral structures in place in some areas. A clinical nurse specialist working with intervention services described how a parent who expressed a concern about their child's development would generally have been referred on by a PHN to a GP or an area medical officer, who would then refer on to the local child and family centre. The child would then be given a full physical

(paediatrician) and a developmental assessment (child and family centre). At this point, in this local area, children would be three years on average and they would then be referred on to intervention services.

It was evident from this interview that there are some effective and efficient structures in place for intervention services once the *diagnosis* is received. In addition there was evidence of efficient structures to support early identification of autism at a local level in some child health centres also. Other initiatives in this area include a sub committee for autism in the Psychological Society of Ireland (PSI) and this group is now developing best practice guidelines, based on an American model (Filipek et al 2006) and these will be published shortly on the PSI website.

Findings of the autism report Ireland (2001) in relation to the low levels of awareness of autism and the lack of training for child health professionals are not unique to Ireland. Studies in the US (Filipek et al 2006) the UK (NAS Report 2006) and Canada show similar findings. The two common factors likely contributing to this situation in these countries and states are the relatively recent understanding of this disorder and the slow process of getting research to practice

3.3   Accessing information on autism services in Ireland

There was no evidence of structures in place at a national level for early identification or intervention services for autism. A search of the HSE websites, Department of Health and Children websites, and discussion with a number of practitioners working in the area failed to find any evidence of a clear policy in relation to services for early identification of autism. While this might be considered a very specific area in terms

38

of policy, there was no evidence of a clear policy at a national level in relation to any aspect of autism services.

It is possible that there may be policy in relation to early identification of developmental disorders in general, but this was not evident on any of the HSE or Department of Health and Children websites. It was at times difficult to access information for this study from the HSE as it is currently undergoing a restructuring process. Trying to locate the department and the person who could provide an answer to queries in relation to structure and services, were not always successful.

However, the HSE is currently taking initiatives to address the problem of health information generally (Health Information: A National Strategy 2004). This report acknowledges the many barriers facing health service professionals and the general public alike, in finding relevant and reliable information and suggest that this is largely due to the fragmented way in which information is held and the under-use or availability of electronic systems. (Health Information: A National Strategy 2004). The issue of accessing useful and reliable information for the public and professionals alike will be addressed in chapter four under ' communicating research to practice'.

This chapter sought to identify what structures were in place in Ireland to support the early identification of autism. The information which was gathered from professionals in the area of autism in Ireland, as well as research findings from studies in this area, will now be discussed under the following headings: The opportunities that exist for early identification; the potential for enhancing the process of early identification; obstacles to best practice currently.

3.4   The opportunities that exist for early identification

Developmental assessments

The process of developmental assessments which are planned to support children's development in the critical early years provides an ideal opportunity for informed health professionals to pick up on developmental delays such as autism. However, evidence suggests that these assessments are not being carried out as consistently or as often as recommended in some regions of the HSE. This results in a lost opportunity for these children and their parents at a time when intervention would be most desirable and beneficial because of the plasticity of the brain in the first three years of development. In one other regions of the HSE, in contrast, where developmental data is stored electronically, the rates of developmental assessment are as high as 90%.

The Child Health Record

The child health record provides a very useful source of information for the parent, and every parent gets this record at the mandatory first visit, 48 hours after the mother and baby are discharged from hospital. However, while this record provides very useful information to support the child's development, there is no information provided specifically in relation to developmental disorders, including autism, and this is again a lost opportunity to alert a parent who has a concern about their child's development, and a lost opportunity to make links for the parent between developmental delay and developmental disorders.

The CHAT items could be quite easily incorporated into the 18 month developmental assessment without alarming the parent, and if the key items are failed, then the full CHAT could be administered which takes approximately 10 minutes. This is a key period of assessment as the next assessment is not until 15-18 months later at 3¼ to 3½ years. In addition, at the previous check, at 7-9 months these behaviours may not be as easy to pick up on.

While very useful guidelines are given for supporting children's speech and language development in this child health record this information is contained in section 3 of the booklet (Appendix 3) under Health and Safety, and would be much more useful, and more likely to be noticed, if it was inserted in the developmental data section (section 4). As mentioned previously, concerns about their child's language development is the main reason for the parent of a child subsequently diagnosed with autism, seeking professional advice.

The child health personnel such as PHNs, GPs and Area medical advisors who carry out these developmental assessments are not provided with training in the area of autism. While there are a number of suitable tools such as the CHAT and M-CHAT to support them in their practice, it would appear that knowledge of these tools among child health professionals is not consistent, and 80% of GPs in a previous study, who were not aware of the CHAT screening tool, indicated that it would be useful for their practice.

3.4.1   Potential for enhancing the process of early identification of autism

The current system and structure for carrying out developmental assessments and recording the results could include *information* such 'red flags' for autism which would support early identification for the parent and the child health professional. This information would increase awareness levels of early indicators for both the parent and the professional. In addition, the provision of training in this area, and access to screening tools, would increase the likelihood of a professional identifying this disorder in early development.

While reference was made to the overlap between indicators for autism and other developmental disorder by two specialists in the area, the interventions would address the common problem areas of development. However, at eighteen months, it is likely that screening tools will be able to differentiate between these disorders in the future, so that interventions can be specifically oriented towards the problem areas which separate these disorders also.

3.4.2   Obstacles to best practice currently

While research for this study identified examples of centres of effective and efficient practice at a local level, it was also apparent that there are a number of barriers limiting best practice in this area of early identification of autism. This includes the lack of any clear structure in relation to early identification of autism, and autism services generally. Despite substantial evidence currently available on the early indicators of autism, it was evident from parent report and from the lack of training provided to professionals that this research is not yet being efficiently disseminated. While this research evidence has been distilled and incorporated in to screening tools to support

early identification, it was apparent that knowledge about the availability of these screening tools is also limited.

It is clear that from this study that health professionals working in this area are faced with many challenges in their daily practice. There is a lack of systems, structure and funding, to support them in their practice in this area of early identification of developmental disorders, including autism. They are also faced with the challenge of accessing up to date research for all the illnesses and disorders they encounter on a daily basis. As identified by one of the contributors to this study, knowledge in this area is not well organised and it is up to the individual to source current research. While this may be manageable to some extent by specialists in this area, though not necessarily time efficient, it would not be realistic for professionals such as PHNs, GPs and AMOs who encounter many disorders and illnesses.

This issue of access to relevant information is also a critical one for parents. As identified by another contributor to this study, there is a time lag of at least two years between a parent first becoming concerned about their child's development to eventually getting a diagnosis. This points to a problem facing parents and professionals alike in accessing information and tools that are up to date, reliable and relevant and from a recognised source. This issue of distilling and disseminating information is the subject of the next chapter, chapter four.

4. Chapter 4 - Communicating research to practice: The role of Information Technology

4.1 Introduction

From the earliest moments in the modern history of the computer (c1950's), scientists and clinicians were captivated by the ability of technology to store and process vast amounts of knowledge and they saw the potential for computers to become perfect 'doctor's in a box' assisting, or even surpassing clinicians with tasks like diagnosis (Coiera 2003). This potential of 'doctor's in a box', otherwise known as 'artificial intelligence' (AI), led to collaboration between enthusiastic computer scientists and healthcare professionals to shape a research programme for a new discipline called Artificial Intelligence in Medicine (AIM). This discipline was primarily concerned with establishing AI programmes for performing diagnosis and making therapy recommendations (Coiera 2003). AIM systems have now expanded to include more aspects of healthcare besides medicine, and incorporating this change, these systems are now more commonly referred to as Clinical Decision Support Systems (CDSS).

While there are some examples of the potential of CDSS having been tapped in clinical practice, use of computer technology in medicine and health care, despite it's proven ability, is still far from routine. The reasons for this are well documented (Coiera 2003) and include issues of computer literacy among healthcare workers as well as the additional effort required to gain knowledge of, and competency in, the use of these

clinical decision support tools for already busy individuals. However, as the generation who have grown up with technology come of age, the integration of Information Communications Technology (ICT) into all aspects of daily life is already apparent, and it's use by healthcare workers is likely to increase at a more rapid rate over time. Because of the very human nature of health and illness, and the importance of human interaction in this process it is perhaps not surprising that CDSS have not yet fitted naturally into all aspects of the process of care. In addition, while the financial benefit of ICT for business and finance became almost immediately apparent, it is still mainly viewed as a cost in the healthcare industry. This is also due in part to the limited numbers of evaluations that have been done in this area (Coiera 2003) and so there has not yet been sufficient opportunity for these technologies to justify their costs. However, it is gradually being accepted that when they fill an appropriate role, the use of CDSS and ICT in healthcare, does offer significant benefits (Coiera 2003).

ICT has also facilitated the explosion of information now available through the use of the Internet and the WWW. It has a benefit which artificial intelligence systems lack, which is its ease of use and in addition its enhancement of human communication through its effect of revolutionising the speed and cost of communicating across long distance, as well as locally. It is not surprising that the impact of the Internet on the way information is created, distributed and accessed made it an attractive tool for academia, and universities were one of the first organisations to adopt this technology, following its initial development as a cold war military research project.

A period of steady growth followed this, with increasing use beyond academia and industry, until the introduction of the WWW which lead to the massive increase in use

as is evident today (Coiera 2003). The Internet and the Web have proven to be powerful tools for the creation and dissemination of information, and its ease of use may in time enhance the use of CDSS, as the public become more familiar with web technology, and as web technology becomes more sophisticated through the incorporation of intelligent systems in the future.

As evidenced above, there are two key aspects of information technology with potential to support healthcare; the use of CDSS in clinical practice and health care generally and the Internet as a user friendly means of accessing health information on line, and is the third most common use of the Internet (Bernstam et al 2005).

However, despite it's ease of access and its ability to disseminate information, the Internet as yet does not appear to have impacted on the process of disseminating research to practice, which is still a lengthy process taking up to seventeen years (ref). This chapter will now look at some of the problems which impede this process. Having identified some of the barriers to this process this chapter will then explore the three objectives outlined in chapter one:

How research is communicated to practitioners in Ireland (4.3)

How information technology is being used, or has the potential to be used to support clinical practice in Ireland (Section 4.4)

How information technology is used internationally to communicate research to practice in the early identification of autism (Section 4.5)

4.2   Communicating research to practice

Even as far back as 1997 Detmer and Shortliffe were pointing to the information crisis

being faced by medical professionals. While medical information was expanding and

changing at an unprecedented rate, important advances identified through research,

was slow getting through to practitioners. They give an example of a study which

showed that fewer than 50% of general practitioners knew that laser surgery could save

the sight of some diabetics, two years after wide publication in medical journals.

However, even then, 360,000 articles were published in medical journals every year.

When considering how busy a typical GP practice is, and the wide area of illnesses and

disorders they encounter, the findings of that study are not surprising.

Robert Hayward (2004) of Healnet (http://hiru.mcmaster.ca/) which promotes that

transfer of medical research to users, describes the overwhelming number, variety and

complexity of decision support tools available to physicians. He describes physicians

as suffering from information hunger in the midst of plenty, as a consequence of

lacking the skills and time to find and assess the information they need.

Goldstein et al (2004) cite research indicating that it takes an average of seventeen

years for new knowledge generated by randomised controlled trials to be incorporated

into practice. While the Internet offers the benefit of ease of access to information,

Coiera (2003) describes the increasing concerns about its potential to spread poor

information. Because electronic information is very cheap to distribute, he points out

that it is cheaper to produce poor quality information that looks good, than high-quality

information, such as evidence based guidelines, that is less well packaged. This puts

producers of poor information at an advantage, he adds, as these producers can flood

the information market with their product. He describes how the relentless growth in

information on the Internet has profound consequences for both information producers

and consumers, as it becomes increasingly difficult for information

producers/researchers to push the information they create to the audience they want to

see it. The consequence of this, he suggests, is that it is not yet clear if we are heading

for an information feast or famine. While there is no limit to the growth in information

Coiera (2003) points out, the attention capacity of the individual is finite. While all the

authors cited on this subject above offer a way forward in addressing this problem such

as improved search technology among other strategies, the problem of speeding up the

process of getting research to practice has still to be resolved.

It is clear that the availability of reliable research information to the consumer offers

many advantages. In addition, it offers significant benefits to the practitioner. It

means that patients can be well informed about their illness and it can thus empower

them to take an active part in managing it. This can save the practitioner time as it

reduces the time needed to inform the patient about their illness, but it also means that

the practitioner needs to be as well informed and up to date concerning all the illnesses

that patients present with, whereas the patient is focusing on just one.

4.2.1   Distilling research evidence to practice using Internet Technology

It is clear that organising and condensing the volumes of current research information

in a manner which makes it easily accessible to the practitioner, is key. In order to

address the issue of providing reliable research information to the patient, web portals,

or websites, which provide high quality information and which can be recommended by the practitioner, offer one possible solution. This approach has already been adopted by the National Health Service (NHS) in the UK and the HSE in Ireland is also incorporating this approach in their documents: 'Making Knowledge Work for Health' (2001) and 'Health Information: A National Strategy' (2004). This will be discussed further in section 4.3.3 of this chapter.

4.2.2   Distilling research evidence to practice using Clinical Decision Support Tools (CDSS)

The second approach is the use of clinical decision support tools which condense many years of research into a 'tool' and thus reduces the information burden on practitioners. An example of this described in chapter 3 is the CHAT screening tool. This tool was first developed in 1992 and incorporated years of research which was condensed in to 14 questions and was then validated on a large population in the UK in 1996 . This tool is quick and easy to use and requires no training. Weed (1997) makes a strong case for the use of these tools to support medical practice because of the limited capacity of the human mind to recall and process large volumes of information. He suggests that only a portion of knowledge is ever 'loaded in to the minds of professionals' and much of this knowledge becomes obsolete. He proposes that medical practice therefore requires tools to extend the mind's limited capacity to recall and process large amounts of relevant variables. Section 4.4 will look at some examples of how these tools are currently being used to support medical practice in Ireland and section 4.5 will look at some examples of CSDD use in the early identification of autism internationally.

4.3   Communicating research to practice in Ireland

This section addresses objective two by exploring how medical research is communicated to practice in Ireland

4.3.1   Access to published research

From information gathered for this study and previous related studies, the most common means of accessing research is individually by consultants and other medical practitioners alike, as opposed to research information being distilled and centralised in relation to a particular disorder or disease.

There are key journals that have particular relevance for the different disciplines such as specialist journals for GPs, PHNs and AMOs including Medline, Journal of Clinical Nursing, The Cochrane Library, the Irish Medical Journal (IMJ) and the British Medical Journal (BMJ). There are also a very significant number of databases available 'on line' to each discipline in nursing and medicine and also through the universities.

However, it would appear from previous research cited in relation to the process of getting research to practice, that the volume of research articles produced in relation to all the disorders and diseases covered by GPs, Public Health Nurses and Area Medical Officers is enormous. This suggests that it would not be realistic or possible for these professionals to read all the current research available. In addition, the research findings then have to be applied to practice, and reading about them is only a first step.

Previous research (Delaney et al 2005) which looked at GPs use of the Internet to access clinical information cited studies which found that GPs seem to have worries regarding Internet use, indicating they believe most of the information they view on the Internet to be correct but don't know how to interpret it. When the volume of research information available is considered, and the many illnesses and disorders which GPs and other health professionals such as AMO's and PHNs deal with in their practice, it would suggest that structures should be put in place to organise, distil and disseminate this information. Rather than each GP, PHN and AMO having to access the many sources, and volumes of information, the provision of a website, or web portal to distil this information on an individual illness basis could be one possibility.

4.3.2   Distilled clinical information

There are a number of initiatives currently in operation for GPs in Ireland which provide very useful services for their members. These include the National Medicines Information Centre (NMIC) the ICGP website, and the GPIT website which will now be described.

National Medicines Information Centre (NMIC) www.nmic.ie This information centre was established approximately twelve years ago for the benefit of healthcare peofessionals. It provides independent information and advice to healthcare professionals in primary and secondary care, particularly general practitioners and community pharmacists, on all aspects of the therapeutic use of medicines. It is based in St James hospital and produces two publications; an 'NMIC' bulletin bi-monthly

and a 'Therapeutics Today' bulletin (Appendix 4) the latter produced in partnership with TCD and published on a monthly basis. Originally these bulletins were paper based only but both are now available on the NMIC website as well as in paper form. Current and previous issues are also available to download from the website.

The NMIC is supported by 7 staff namely a medical adviser, a chief pharmacist, three senior medicines information pharmacists, one basic-grade rotational pharmacist and full-time secretarial support. When a bulletin topic is decided on, staff source the relevant databases and journals and relevant textbooks. The information is then distilled and written up in a standard format which includes an introductory paragraph giving prevalence rates and symptoms of a particular illness or disorder. This is followed by a brief history of the illness, aetiology, diagnosis and guidelines for the management of the illness both pharmacologically and non pharmacologically. Common pitfalls in diagnosis and management are then outlined and it concludes with a brief summary of the key issues to be considered.

Irish College of General Practitioners Website (ICGP) http://www.icgp.ie.
Another resource available to GPs is The Irish College of General Practitioners (ICGP) website. This website provides a wide variety of useful information in relation to all aspects of GP practice. It has a very extensive sitemap and the Turning Research into Practice (TRIP) database, http://www.tripdatabase.com/ is an example of one useful resource which has been approved for use by ICGP. The TRIP site was established in 1997 by two doctors as an evidence based medicine site and when it was found that many clinical questions could not be answered by this approach alone, peer review journals and guidelines were added as information sources. A search can be

undertaken using clinical areas or search title or search title plus text. A large number of clinical areas are covered in full text format e.g. Pregnancy and Childbirth. External links to related websites are also provided. TRIP describes itself as 'the Internet's leading resources for Evidence-Based Medicine, allowing users to easily and rapidly identify the highest quality evidence from a wide range of sources'.

National General Practitioners Information Technology Group (GPIT) www.gpit.ie

The GPIT Group were established by the department of Health and Children to help develop computerisation in general practice and to encourage better electronic communication between general practice and other healthcare sectors. This website seeks to promote a greater appreciation of the role that knowledge management and communications technology can play in progressing an integrated, quality based and patient centred health service. Some examples of CDSS software approved by this group will be described later in section …..

HSE Immunisation website (http://www.immunisation.ie/en/

This site was developed by the HSE to improve the uptake of childhood vaccination. All information on the site is reviewed to ensure it is scientifically accurate. The site content is monitored and regularly updated by a team of public health doctors (including members of the Royal College of Physicians of Ireland National Immunisation Advisory Committee) and staff from the National Immunisation Office. It provides details on all vaccines for children as well as the recommended schedule for these vaccines.

4.3.3   Planning for the future: The HSE, ICT and Health Information Strategy

Former Minister for Health Micheal Martin acknowledges that the pace at which

information is generated could cause a serious information gap between the public,

clients/patients, the professionals, the planners, the policy makers and the research

community (Health Information: A National Strategy 2004). Indicating the response

of the HSE to this challenge, he makes reference to the vision, goals and objectives of

the National Health Information Strategy as set out in a number of documents; Quality

and Fairness: a Health System for You (2001), Primary Care: A New Direction (2001),

and the Health Service Reform Programme (2003) all of which emphasise the

objective of ensuring that health information becomes more readily available and

appropriately used through the sector. The primary aim of the National Health

Information Strategy is to recommend the necessary actions to rectify current

deficiencies in health information systems and to put in place the frameworks as

required, ensuring the optimal development and utilisation of health information. This

is seen as essential to the successful implementation of the Health Service Reform

Programme. Information is one of the six frameworks for change in the Health

Strategy *Quality and Fairness: a Health System for You (2001).*

The importance of progressing the information framework has also received repeated

emphasis in the Deloitte and Touche report on *Value for Money in the Health Services,*

the Primary Care Strate*gy Primary Care: A New Direction (2001),* the Brennan and

Prospectus Reports and, more recently, in the government's decision in relation to the

Health Service Reform Programme. These reports acknowledge the many barriers

facing health service professionals and the general public alike, in finding relevant and

reliable information and suggest that this is largely due to the fragmented way in which information is held and the under-use or availability of electronic systems. (Health Information: A National Strategy 2004). One recommendation to address this fragmentation and the lack of standard, reliable and integrated solutions for utilising health information is the development of an Internet based Health Information Portal and this is proposed in the National Strategy document (2004).

Health Information Portal

It is intended that this Health Information Portal will provide a range of information and information based services for the public, for health professionals, for researchers and for policy makers. Of particular relevance for this study is that this portal will be developed in close collaboration with the Health Service Executive and the Department of Health and Children. It is also envisaged that as the capacity of ICT continues to develop, as information sources become more standardised and as the framework for ehealth service delivery is extended, so also may the range of services made available directly through or linked via the Health Information Portal can be extended and improved.

Of particular relevance for this study, the information on health issues and concerns will cover such topics as best practice guidelines in areas of preventive health such as *screening,* vaccination, oral health and lifestyle, as well as the personal management of health concerns such as asthma, hypertension, diabetes and cancer. It is also stated in this Strategy document (2004) that this will be undertaken on a phased basis and will draw extensively on national and international expertise and critically, will require that procedures are in place to ensure information is kept accurate and up to date.

- Developing health information systems

- Promoting and implementing structured programmes of quality assurance

- Reviewing and reporting on selected sets of services

- Overseeing accreditation

- Developing health technology assessment

While this proposal is still in the early stages of implementation, with the objectives and functions of the overseeing body, the Health Information Quality Authority (HIQA) still to be set out in primary legislation in 2006, it is encouraging evidence of structures being put in place to address some of the barriers to health information as identified throughout this report, to address the health information needs of the public and professionals alike. The use of information technology to to support clinical practice in Ireland will now be discussed.

4.4   How is information technology being used, or has the potential to be used to support clinical practice in Ireland?

The key way evidence based research will be conveyed to clinical practice in the future will be through CDSS. The vision for the future, in a fully electronic world, is that the ECHR will include active DSSS. When particular patient data is entered, alerts, reminders and diagnostic tools will be triggered and these tools will embed current best practice. Some examples of tools to support clinical practice in Ireland will now be described.

4.4.1   Apollo Medical (www.apollo-medical.com/products/clinical.htm

This software is available on the 'Accredited list of products' on the GPIT website described in section 4.3.2 and is a clinical management system for enabling fully electronic medical records in clinics. It has a user friendly Windows interface connected to a powerful clinical data store based on the European medical record standard CEN- TC251. This enables all members of a multi disciplinary healthcare team to record and share patient information easily and effectively.

4.4.2   Disease Management System DABL (www.dabl.ie)

This software is also available on the 'Accredited list of products' on the GPIT website. An example of one of their products is a system for the diagnosis and management of hypertension. DABL design systems that are 'based on best practice incorporating the latest guidelines and knowledge from clinical research. They are a partnership of internationally recognised medical experts combined with experts in management techniques and health informatics. All DABL systems are web based and enable the sharing of dabl systems and data locally, nationally and internationally

4.4.3   Electronic Patient Record (EPR)

This has recently been introduced in St. James's hospital and is at an early stage of development. It enables finding a patient on a hospital list and gives demographics such as patient name and address, date of birth, consultant name, and number of visits and what tests are finished and pending. It is currently being used mainly for order

coms such as laboratory tests and radiography. The use of information technology internationally to support the early identification of autism will now be discussed.

4.5 How is information technology being used internationally to communicate research to practice in the early identification of Autism?

4.5.1 First Signs Website

First Signs Website is an American website dedicated to the early identification of autism and other developmental disorders: http://www.firstsigns.org . The goals of this organisation are to improve screening and referrals and to lower the age at which young children are identified with autism and other developmental disorders. They are creating a national model for disseminating key information about early warning signs, the need for routine screening, and the treatment options available to parents of children diagnosed. The First Signs program provides practitioners with tools and training, and parents with education and support, to help young children stay on a healthy developmental path. Studies in the US have shown that 70% to 80% of children in need of services are not identified by their primary care provider. There were similar findings in the autism report in Ireland in 2001. Consequently, children can miss opportunities for intervention during the most critical time of brain development.

By providing up to date research on early indicators and screening tools for Autism for Health care professionals and parents, this website brings together key information for early identification and intervention. According to the site manager, this website is getting about 47,000 visitors per month (1,500 a day) and 716,000 hits per month and these come from all over the world.

This website also provides a link to a decision support screening tool called Parents'
Evaluation of Developmental Status (PEDS) which can be completed on line
http://www.pedstest.com/index.php. It is a developmental screening test and is
suitable for children 0-8 years. The parent completes this test on line and if responses
indicate a developmental problem then the M-CHAT is triggered. The results are then
e-mailed to the parent along with a letter of referral and there is a charge of $9.95 for
this test.

4.5.2   TRIP database

In contrast to First Signs, dedicated to developmental disorders, a general clinical
information website such as TRIP provides very patchy information on autism. Recall
from section 4.3.2 that this site is linked from the ICGP site and focuses on evidence
based medicine. The TRIP website allows three free searches to any user and as it
addresses the topic for this study, turning research into practice, a search was
conducted using the keywords 'autism', and 'screening tools'. The response to this
search was zero in all categories. However, a wider search using 'autism' only as a
keyword search provided one result under 'Evidence Based Synopses'. Clicking on
this result led to an evidence based paediatric website hosted by the University of
Michigan. This website provided a report summary of key evidence in relation to the
MMR and Autism, and the results of another recent study which had failed to find a
link.

However, doing a further search a few weeks later to see if any additional information
had been added in that time was more productive http://www.tripdatabase.com/index.
html. On this occasion using keywords 'autism' and 'screening tools' again, there
were two results for systematic reviews, nine results for guidelines in North America,

one for 'guidelines in Europe' and seven e-text books. The most useful of these proved to be a link to 'The paediatrician's role in the diagnosis and management of autistic spectrum disorder in children (2002).' This link provided twelve guidelines for paediatricians and drew attention to the key indicator of language delay. However, while making reference to the need for screening and diagnosis tools, no tools were specified and the usefulness of these guidelines for a paediatrician or practitioner not familiar with this disorder was very limited.

Another link which looked promising was 'Autism Spectrum Disorder: Best practice guidelines for screening, diagnosis and assessment.' This was produced by a 'National Guidelines Clearinghouse' in 2001, http://www.guideline.gov but on closer examination the guidelines were vague, and again for a practitioner with very little knowledge of the disorder, these guidelines would not be helpful or informative. The most useful link subsequently proved to be the link to 'guidelines in Europe'. At first glance, for this reader very familiar with the area, the authors are well established researchers in the field of autism and it is likely a very useful document for a specialist in the area. However, the document is fifty seven pages in length and again this would not be suitable for the busy practitioner looking for best practice guidelines, and ideally, a link also to a screening tool such as the CHAT and M-CHAT described in Chapter 2.

This last search, if undertaken by a practitioner looking for a screening tool for autism, or best practice guidelines, using the TRIP database would not have proven very useful. It again illustrates the problem faced by these practitioners when looking for information or guidelines. The first search produced no relevant results and while the second search a few weeks later produced a very significant increase in available

information, the time taken to go through these results would likely have proven unproductive for the practitioner unfamiliar with the area.

However, it should be noted that there was some very useful research material for a team of researchers, such as that employed by the National Medicines Information Centre (NMIC) in St. James Hospital described earlier. It again points to the need for centralizing key information on a particular disorder/illness such as Autism, and having a support team in place to do this. Another factor which is likely impinging on the availability of relevant information on screening tools for this disorder, is that a lot of the research in this area is related to behaviours, and there are as yet no specific biological indicators. Therefore, much of the research evidence tends to be related to genetic factors, gastrointestinal factors and the MMR controversy. This again supports the benefit of the provision of information dedicated to a specific illness or disorder, which can then incorporate the findings from all related disciplines.

4.6   Summary

This chapter addresses three of the objectives of this study as follows

How research is communicated to practitioners in Ireland (Section 4.2)

How information technology is being used, or has the potential to be used to support clinical practice in Ireland (Section 4.4)

How information technology is used internationally to communicate research to practice in the early identification of autism (Section 4.5)

4.7 Conclusion.

The problems inherent in the process of getting research to practice are evident. Too much information for the human processor (Weed 1997), and a bewildering amount of tools to choose from can be daunting for the average practitioner not yet familiar with CDSS technology. However, there are signs that this technology is beginning to be used as evidenced on the GPIT website and in addition the introduction of the EPR in St James hospital.

The benefits which CDSS technology offer for the patient and practitioner, as described by Weed (1997) are significant. They provide evidence based tools which incorporate the latest research and encode best practice for the busy practitioner. However, it would appear from this study that the use of websites for the dissemination of research information in Ireland such as the NMIC, GPIT and ICGP websites are the most common use of technology in the health sector at the moment. The HSE proposal for a Web Portal to provide evidence based research on a range of illnesses/disorders to the general public and health professionals will also incorporate this technology.

The First Signs website described in this chapter provides a useful prototype for an Irish website. It also provides an example of how a web enabled database could support early identification of autism through the use of a decision support tool for developmental screening on line such as the PEDS example.

Chapter five will now consider the gaps identified in chapter three which limit the early identification of autism, and explore the potential for some of the technologies described in chapter four to address these gaps.

5. "Analysis: How can ICT support early identification of autism in Ireland?"

5.1   Introduction

So far this dissertation has described why early identification of autism is important (chapter 2), what the gaps are in the health system which limit early identification (chapter 3) and some examples of how ICT is being used in Ireland and internationally to support clinical practice (chapter 4). Chapter five will now look at how some of the technologies described in chapter 4 could be utilised to resolve some of the barriers to early identification of autism described in chapter three.

Ireland is not alone in its lack of structures and supports in the area of early identification of autism and recent reports from the UK, the US and Canada describe similar experiences. Understanding of this disorder is relatively recent, and understanding of *early* indicators for this disorder more recent again. Considering the time it takes to get research to practice as was described in chapter four, the current lack of knowledge is perhaps not surprising.

Two approaches to speeding up the process of getting research information on early identification of autism to child health professionals and parents through the use of information technology will now be proposed. The first approach will suggest the most efficient method of distilling and disseminating research on early identification of autism to child health professionals and parents taking account of current ICT strategy

in the HSE. The second approach will describe the potential for more sophisticated ICT systems such as decision support tools which could be developed concurrently.

5.2   Proposal 1. Create a website dedicated to early identification of autism to be incorporated in to the proposed HSE Web Portal

Websites are already in use in many areas of the health service such as the immunisation website to promote vaccine uptake and the NMIC website in St. Jame's hospital providing pharmacological advice and information on a range of illnesses for GPs and pharmacists. The ICT strategy for the HSE in the future is to develop a web portal to incorporate information on a range of illnesses for health professionals and the public alike. While this strategy is still in the early stages of implementation, the development of a website similar to the US based website 'First Signs' http://www.firstsigns.org/ (see appendix X for site map) could be incorporated into this proposed web portal. This could be a helpful first step in addressing the current information needs of parents and child health professionals about the early indicators of autism.

This website would be required to meet the quality standards as set down by the WHO, which is a requirement of the HSE for their websites. Existing resources to support websites within the HSE could be shared, such as technical support for maintaining websites, and systems for updating these websites such as that utilised by the NMIC could also act as a model. As indicated by requests to RTE radio for a website providing information on autism there is likely to be strong demand for this website.

The significant number of 'hits' which the US based 'First Signs' website gets (1500 visitors per day) also suggests there is likely to be high demand for this information.

Web based support for PHNs, GPs and AMOs

It is proposed that this website would follow the current model of the 'First Signs' website www. and would provide current research information on early indicators of autism for parents and child health professionals alike. In addition, screening tools for autism would be available to download, such as the CHAT and M-CHAT, and directions for using these tools would be given (which require no training). In addition, Ireland specific information would be provided on this website such as a protocol to follow from first concerns about a child to the point of getting a diagnosis and where to get information and support. An index of best practice guidelines for all illnesses/disorders will also be provided on the proposed HSE web portal. This website could also have subdivisions into different regions as services vary in different regions of the HSE. 'Not for profit agencies' for example are very active in some regions of the HSE but not in all. In addition, the referral process may vary to some extent from region to region currently, and region specific information would be important to clarify this for parents and child health professionals alike.

All professionals who contributed to this study indicated that an Ireland specific website would be the best approach to take as it could be incorporated into current ICT strategy within the HSE, and it would be a reliable source of information for the public and health professionals alike. It would also save these two groups from time consuming and time wasting searches on the Internet. The HSE proposal states that it

will draw extensively on national and international expertise and procedures will also

be out in place to ensure information is kept accurate and up to date. Both parents and

child health professionals could be share the same evidence based research information

and this would support understanding for both, on what is a complex disorder. It

would also support the continuing professional education for child health professionals

which is becoming compulsory for this sector. The HSE proposal states that it will

draw extensively on national and international expertise and procedures will also be

out in place to ensure information is kept accurate and up to date.

The standardisation of the layout ('look and feel') of these websites would also offer a

benefit to the child health professionals and public as they would become familiar with

this standard which in turn would encourage use and increase awareness of the other

websites on illnesses/disorders on this portal.

5.3   Proposal 2, for a decision support system to support child health professionals in

the early identification of autism

5.3.1   Electronic Child Health Record (e- CHR)

The structures currently in place for developmental assessments where a child has six

developmental assessments from birth to 3 1/2 years, and the provision for storing this

data electronically in all HSE regions in the future, provides the necessary elements to

support an e-CHR. This is the only period of the child's development where *routine*

checks are carried out and recorded by PHNs, AMO's and GPs, and in addition

information is recorded within days of the child's birth. Thus an e-CHR for this

developmental period 0-3½ should not pose the same problems that a lifelong e-record might, as a paper record of this period already exists. As this data is stored centrally, access could be provided to key professionals involved in children's early development such as PHN's, GP's and AMO's. In addition, specialists such as paediatricians, child psychologists and child psychiatrists could also have access to this information if a child is referred on to them with a developmental problem.

5.3.2   Decision support tool for early identification of autism

It was evident from chapter four that GPs in Ireland are beginning to take advantage of decision support software. While exact figures were not available for this study, it is likely that this is a trend that will continue to develop in the future as more GPs become familiar with this level of technology. As indicated by Weed (1971, 200?) primary care physicians encounter a wide range of illnesses in their practice and decision support tools which incorporate best practice guidelines and which can be updated as new research becomes available, provide great support for the busy GP. As is evident, GPs have little, if any, training in developmental disorders, including autism, although they may conduct developmental assessments. Therefore, a decision support tool for developmental screening which includes autism screening, could support GPs in their practice. Previous research identified that more than 80% of GPs would be supported in their practice through the provision of a screening tool for autism. Many of the elements needed for the development of a decision support tool for the early identification of autism are already available. Best practice guidelines were published recently (Filipek et al 2006) and it is also planned that the HSE will have an index of best practice guidelines on their proposed Web Portal.

The CHAT and M-CHAT screening tools are also suitable for adaptation to a decision support system as they are based on yes/no answers. As described in chapter 2, the CHAT consists of fourteen items and the key items look at behaviours which if absent at 18 months put the child at risk of a social communication disorder such as autism (see Appendix I for further information on this tool). If a child fails *five* key items, they have a high risk of developing autism. If the child fails *two* key items, they have a medium risk of developing autism. It is recommended that any child who fails the CHAT should be re-screened one month later.

A decision support system incorporating best practice guidelines for developmental *assessments* and developmental *screening* for disorders such as autism could be embedded in the e-CHR. An example will now be given of how this system would operate when a parent and child are due a *routine* developmental assessment at 18 months (when the CHAT is designed for use):

The parent would be notified automatically of this *routine* 18-month developmental assessment in advance and an appointment date and time would be included in this notification. The GP would be automatically alerted of the developmental assessment on his/her calendar for that date. When the parent and child arrive for their appointment, the GP would follow the *standard* procedure for carrying out developmental assessments following best practice guidelines as incorporated in this e-CHR. As recommended in chapter three, the *standard* questions and observations incorporated in this assessment would be based on current evidence based research. The DSS would broadly proceed as follows:

1. **IF** a predetermined number of 'no' answers are returned when the responses are computed by the system (indicating fail) when the *standard* developmental assessment is complete

2. **THEN** the CHAT screening tool will automatically be triggered along with an explanation to the GP of why this is being triggered. The GP can then proceed with the CHAT screening tool.

3. **IF** the number of 'no' responses compute to *either* 2 or 5 (indicating medium or high risk for autism)

4. **THEN** an appointment is automatically made for a further screening with the CHAT in four weeks time.

(At this point a standard information sheet, incorporating *personal* data tailored to the child's developmental level and addressing the problem areas identified by the CHAT such as social responsiveness, would automatically be produced for the parent. This information sheet would explain why they are being given a follow up appointment, as well as details of useful information resources for support).

IF this second CHAT screening is failed one month later

THEN the GP system automatically refers the child for a full developmental assessment to a specialist developmental clinic such as 'child and family centres' mentioned in chapter 3. This will be done automatically if these centres are also linked to the e-CHR or manually, if this is not yet in place.

(As the M-CHAT has not yet been fully validated for population screening (ie used for screening for all children) the CHAT was used in this example).

5.3.3 Data Mining

Another potential benefit of having this data stored centrally is that data mining technology could also be used by researchers to identify *patterns* in the data of children who receive a diagnosis for a developmental disorder such as autism. This could feed back in to the developmental assessment so that any additional information gathered from this data mining process could be added to the developmental assessment process and to screening tools. In addition, when research identifies other biological or environmental factors which may contribute to the development of this disorder, these factors could then be added to the developmental assessment checks, and thus further support the early identification process. An example of this is adding the 'head tilt test' referred to in chapter three, to the developmental assessment, if evidence from current research in this area supports the benefit of that.

5.4 Finding out about the Website and DSS

As the HSE will likely launch an advertising campaign to make health professionals and the public aware of the health information Web Portal, this website would also be included in that campaign. In addition, advice on how to make the public and health professionals aware of this website could be sought from the relevant department in the HSE. Their website which was designed to improve immunisation uptake was very successful and this strategy could be adopted to advertise this website also.

Consultation with GPIT would also be undertaken to advice them of the potential for a decision support tool and to include them in the process of development of this tool, so that it would satisfy the necessary criteria. In addition, a link would be provided from their website to the HSE health information portal as well as a direct link to the website for any GP who puts in a key word search for information on 'early indicators of developmental delays' or 'early indicators of autism'.

PHN's and AMO's with the necessary hardware would also be automatically linked with the e-CHR, and this decision support tool and would have access rights as designated by the HSE for all child health professionals. The website would also provide information on the e-CHR and the DSS and this would also increase awareness levels of the availability of this tool among this group. However, it is hoped that in time this information will be provided during the training process for all child health professionals also, and training for all child health professionals on the early indicators of autism is a recommendation of all the reports mentioned in chapter three from Ireland, the UK the US and Canada.

5.5   Summary

This chapter has brought together the findings from chapters three, four and five to answer the question:

Can Informatics bridge the gap between research and practice to support the early identification of Autism?

Two approaches have been suggested for addressing the gaps identified in chapter three which all relate to *knowledge* and *information* on early indicators of autism. While substantial research information and screening tools are available for this developmental disorder, the professionals and parents who need this information don't have it. There is little evidence of any structures or organisation in place in the HSE such as training for professionals and information for parents, to support the early identification of autism. This can be explained by the fact that autism is a relatively recent disorder with behavioural symptoms rather than biological symptoms and the process of getting behavioural research to medical practice is slow.

The first proposal is for a website which would be incorporated in to the planned HSE web portal and would include the following information

- Up to date information for parents and professionals on the early indictors of autism
- Information on the use of screening tools for early identification of autism such as the CHAT and M-CHAT, including the strengths and limitations of these screening tools
- Best practice guidelines on early identification of autism for child health professionals
- Information for parents and child health professionals on the referral process and information on how to support their child's development if immediate assessment is not available
- Information specific to the different regions of the HSE such as referral processes and waiting lists

- Links to other approved sites providing relevant information such as evidence based interventions for children with autism

This website would address some of the information needs of child health professionals and parents. While it does not address the training needs of child health professionals, it would create more awareness of the need for training in developmental disorders in the child health sector.

The second proposal could be developed alongside this website to bring together the elements which already exist to support an e-CHR, such as a *system* for developmental assessments and an electronic database of developmental assessment *results*. A decision support tool such as the CHAT could be incorporated into this e-CHR as described and this would overcome to some extent the low levels of awareness of early indictors of autism among GPs because of the lack of training and information available to them in this area.

While the limitations of the CHAT screening tool have been described, evidence to date suggests that the M-CHAT will overcome the sensitivity problem of the CHAT. However, as modified versions of this tool become available, these improvements can be incorporated into decision support systems already in place. The main contribution of these two proposals however, is their potential to increase the awareness levels of current research on early indicators of autism among child health professionals and parents and thus support the best outcomes for children and their parents.

Chapter six will now summarise the findings of this dissertation and make

recommendations for future study.

6. Conclusions and Recommendations

This dissertation was an exploratory study. It sought to answer the question ' Can Informatics bridge the gap between research and practice to support the early identification of Autism'? In order to answer that question an understanding of why early identification of autism was important was first addressed. The author is a recent psychology graduate with an interest in child development and developmental disorders. In the course of previous undergraduate research it became apparent that there was a wide gap between what was currently being published in the field of autism concerning early identification and the application of this knowledge in practice. An example of this was the CHAT screening tool which was first developed in 1992 and was subsequently validated on a large population of children of 18 months in the UK in 1996. However, in 2004, a sample of GPs who participated in an undergraduate study was not aware of this tool and 82% indicated that it would be useful in their practice.

This exploratory study identified that the problem of getting research knowledge to application in practice is not unique to the area of autism and is a problem in medicine generally. It is especially a problem for practitioners who work in the area of child health and development as they encounter a wide range of illnesses and disorders and find it impossible to keep up to date with the vast amounts of research information available to them in journal format. Weed (1997) suggests that modern information tools offer a solution to this problem. The CHAT screening tool is an example of this. Many years of research evidence is incorporated in to this screening tool and yet there is no requirement for the child health professional to have any knowledge about autism, to use this tool. This incorporation of knowledge into a tool such as the CHAT

addresses one of the challenges facing the child health professional. The next challenge is how to make the child health professional aware of the existence of this tool?

In order for child health professionals to have knowledge of tools such as the CHAT to support early identification of autism, there is a need for structures to be in place to organise and distil this information in an effective and efficient manner. However, it is clear that the structures are not yet in place in Ireland for training and for organisation of information.

Parents, often the first to notice a problem with their child's development, do not have the professional support and information resources they need to make the link between their child's developmental problems and autism. As a consequence, they embark on a solo journey trying to find the information they need to support their child's development. This journey takes a minimum of two years according to an expert in the field of autism diagnosis, and when they eventually get a diagnosis the parents, response is: 'if only I had known this two years ago'. These parents often get their information from the Internet and while this can be a very useful resource, the information is not always evidence based and reliable. In addition, because of the complex nature of this disorder, getting all the necessary information takes a long time and this results in the loss of valuable intervention at a crucial period of their child's development.

It is evident that the information that parents' need is available, but it is difficult to access because there are no structures in place to make evidence based research

information readily available to these parents in Ireland. The increases in funding available for autism research in recent years has contributed to an increase in knowledge which is now leading to more refined areas of expertise within the autism field. This again demonstrates the challenge for informaticians to organise this information in a way that makes it readily accessible to the people who need it.

This study has proposed two ways of using ICT to support the process of getting research on early identification of autism to the people who need it, namely parents and child health professionals. The first is a proposal for a website to be incorporated in to the proposed HSE Web Portal which will be developed to address the health information needs of parents and child health professionals. This proposed Web Portal which will be set up under the supervision of the Health Information Quality Authority (HIQA) will provide a central resource for evidence based research and information for parents and health professionals alike. Thes website would help to address the gaps identified in this study such as lack of information for parents and professionals on early indicators of autism and would also provide information on suitable screening tools for use by child health professionals.

The second proposal for an electronic child record (e-CHR) would incorporate a decision support tool for developmental assessments and would follow best practice guidelines which have recently been published by Filipek et al (2006). This decision support tool would provide the GP with up to date best practice guidelines and screening tools at the point of care. It would also provide information for parents on why their child may need to be screened again and contact details for other information resources.

These two proposals would provide a structured system for the provision of information and screening tools to support the early identification of autism for child health professionals. They would also bridge the gap in information needs of parents concerned about their child's development. This structured provision of information would help address the lack policy and structure in the health service in relation to the early identification of Autism.

6.1   Recommendations

Arising from this study the following recommendations are made to bridge the gap between research and practice using ICT to support the early identification of autism:

The development of a website to provide information on early indicators of autism for parents and child health professionals in consultation with the HSE

Consultation with parents and child health professionals about their information needs in relation to early identification of autism

Consultation with the HSE and experts in the field of early identification of autism in Ireland about the procedures to be put in place to ensure information is accurate and kept up to date on this website.

The provision of funding for the development of this website as provided for under the HSE ICT strategy

It is recommended that the HSE collaborate with the ICGP and GPIT to progress the development of an e-CHR. The benefits of this for all child health professionals are not limited to early identification of autism and other developmental disorders. It also

provides a model which can be built on for the future development of a lifelong EHR, especially for children with long term disabilities and illnesses who will need support throughout their lives.

It is recommended that the Child Health Record be reviewed on a regular basis to reflect evidence based current best practice in developmental assessments and early identification of developmental disorders. However, once all assessment data is stored electronically, maintenance and updates become much simpler, take immediate effect and make document control a much simpler process. The online document will become the current document and this makes the use of out of date documents less likely

It is recommended that multi disciplinary collaboration be encouraged between child health professionals and ICT experts to maximise the benefits of an e-CHR for children's health

6.2   Limitations of the study

It was not possible to do a full in depth analysis of autism services in the HSE and 'not for profit' sector and it is possible that early identification services exist on a more widespread basis. However, this information was not easily accessible and was not available on Government or HSE websites.

This study did not address the important issue of the provision of training for public health professionals on the early identification of autism because of time and word

constraints. However, ICT could also support this process and this will be explored in future work.

Appendices:

The National Autistic Society

Checklist for Autism in Toddlers (CHAT)

This information was supplied by Sally Wheelwright, University of Cambridge.

For information on permission to reproduce this page (or any other material on the NAS website) see the link in 'Relates resources' at the bottom of this page.

The Checklist for Autism in Toddlers (CHAT) is a screening instrument which identifies children ag months who are at risk for social-communication disorders.

Questions and answers about the CHAT

i. **What is the CHAT?**
   The Checklist for Autism in Toddlers is a short questionnaire which is filled out by the paren a primary health care worker at the 18 month developmental check-up. It aims to identify cl who are risk for social-communication disorders.

ii. **How is the CHAT administered?**
   The CHAT can be found below. It consists of two sections: the first nine items are question asked to the parents, and the last five items are observations made by the primary health c worker. The key items look at behaviours which, if absent at 18 months, put a child at risk f social-communication disorder. These behaviours are (a) joint attention, including pointing show and gaze-monitoring (eg looking to where a parent is pointing), and (b) pretend play (pretending to pour tea from a toy teapot).

iii. **How is the CHAT scored?**
   The CHAT is very easy to score. There are five key items: A5 (pretend play), A7 (protodecl pointing), Bii (following a point), Biii (pretending) and Biv (producing a point). If a child fails key items, they have a high risk of developing autism. Children who fail items A7 and Biv h medium risk of developing autism.

iv. **What happens if a child fails the CHAT?**
   Any child who fails the CHAT should be re-screened approximately one month later. As wit screening instrument, a second CHAT is advisable so that those children who are just sligh delayed are given time to catch up and also to focus efforts on children who are failing consistently. Any child who fails the CHAT for a second time should be referred to a specia clinic for diagnosis since the CHAT is not a diagnostic tool.

v. **What happens if a child passes the CHAT?**
   If a child passes the CHAT during the first administration, no further action needs to be take However, passing the CHAT does not guarantee that a child will not go on to develop a social-communication problem of some form and if parents are worried they should seek re

vi. **What are the advantages of the CHAT?**
   Because there is no single known medical cause of social-communication disorders, it is ve unlikely that there will be a medical test available in the near future. Whatever the cause of problems, the behavioural characteristics have been identified and this is what the CHAT is based on. In addition, the CHAT is cheap, quick and easy to administer. Currently, autism i rarely detected before the age of three and for the other social-communication disorders, a

detection can be even later. The CHAT, however, is administered when the child is 18 mor old. The earlier a diagnosis can be made, the earlier intervention methods can be impleme and family stress reduced.

vii. **How can further information be obtained?**
If you have any questions about the CHAT, please contact:

Sally Wheelwright
Autism Research Centre
Cambridge University
Douglas House
18b Trumpington Road
Cambridge CB2 2AH, UK

Tel: 01223 746057
Fax: 01223 746033
Email: sjw18@cam.ac.uk

The CHAT

To be used by GPs or Health Visitors during the 18 month developmental check-up.

Section A: Ask Parent:

1. Does your child enjoy being swung, bounced on your knee, etc?

YES/NO

2. Does your child take an interest in other children?

YES/NO

3. Does your child like climbing on things, such as up stairs?

YES/NO

4. Does your child enjoy playing peek-a-boo/hide-and-seek?

YES/NO

5. Does your child ever PRETEND, for example, to make a cup of tea using a toy cup and teapot, pretend other things?

YES/NO

6. Does your child ever use his/her index finger to point, to ASK for something?

YES/NO

7. Does your child ever use his/her index finger to point, to indicate INTEREST in something?

YES/NO

8. Can your child play properly with small toys (eg cars or bricks) without just mouthing, fiddling or dropping them?

YES/NO

9. Does your child ever bring objects over to you (parent) to SHOW you something?

YES/NO

Section B: GP or HV Observation:

i. During the appointment, has the child made eye contact with you?

YES/NO

ii. Get child's attention, then point across the room at an interesting object and say 'Oh look! There (name of toy!)' Watch child's face. Does the child look across to see what you are pointing at?

YES/NO*

iii. Get the child's attention, then give child a miniature toy cup and teapot and say 'Can you make of tea? ' Does the child pretend to pour out tea, drink it, etc.?

YES/NO**

iv. Say to the child 'Where's the light?', or 'Show me the light'. Does the child point with his/her ind finger at the light?

YES/NO***

v. Can the child build a tower of bricks? (If so how many?)
(Number of bricks:.............)

YES/NO

---

* (To record YES on this item, ensure the child has not simply looked at your hand, but has actual looked at the object you are pointing at.)

** (If you can elicit an example of pretending in some other game, score a YES on this item.)

*** (Repeat this with 'Where's the teddy?' or some other unreachable object, if child does not unde the word 'light'. To record YES on this item, the child must have looked up at your face around the of pointing.) **Copyright of MRC/SBC 1995**

The CHAT research team

Guy's Hospital
Newcomen Centre, UMDS, Guy's Hospital, St. Thomas Street, London SE1 9RT, UK
Tony Cox, Gillian Baird, Auriol Drew, Kate Morgan, Natasha Nightingale and Mary Marden

University of Cambridge
Department of Experimental Psychology, Downing Street, Cambridge, CB2 3EB, UK
Simon Baron-Cohen, Sally Wheelwright

University College London

Behavioural Sciences Unit, Institute of Child Health, 30 Guilford Street, London WC1N 1EH, UK
Tony Charman

Department of Human Communication and Science, Chandler House, 2 Wakefield Street, London WC1N 1PG, UK
John Swettenham

Further reading

Baron-Cohen et al. (1992) Can autism be detected at 18 months?: the needle, the haystack and the CHAT. *British Journal of Psychiatry*, **161**, pp. 839-843.

Baron-Cohen et al. (1996) Psychological markers in the detection of autism in infancy in a large population. *British Journal of Psychiatry*, **168**, pp. 158-163.

Baron-Cohen et al. (2000) Early identification of autism by the CHecklist for Autism in Toddlers (C *Journal of the Royal Society of Medicine*, **93**, pp. 521-525.

Related Resources
Re-using material from any NAS media

M-CHAT

Please fill out the following about how your child **usually** is. Please try to answer every question. If the behavior is rare (e.g., you've seen it once or twice), please answer as if the child does not do it.

1. Does your child enjoy being swung, bounced on your knee, etc.?   Yes   No

2. Does your child take an interest in other children?   Yes   No

3. Does your child like climbing on things, such as up stairs?   Yes   No

4. Does your child enjoy playing peek-a-boo/hide-and-seek?   Yes   No

5. Does your child ever pretend, for example, to talk on the phone or take care of dolls,   Yes   No

    or pretend other things?

6. Does your child ever use his/her index finger to point, to ask for something?   Yes   No

7. Does your child ever use his/her index finger to point, to indicate interest in something?   Yes   No

8. Can your child play properly with small toys (e.g. cars or bricks) without just   Yes   No

    mouthing, fiddling, or dropping them?

9. Does your child ever bring objects over to you (parent) to show you something?   Yes   No

10. Does your child look you in the eye for more than a second or two?   Yes   No

11. Does your child ever seem oversensitive to noise? (e.g., plugging ears)   Yes   No

12. Does your child smile in response to your face or your smile?   Yes   No

13. Does your child imitate you? (e.g., you make a face-will your child imitate it?)   Yes   No

14. Does your child respond to his/her name when you call?   Yes   No

15. If you point at a toy across the room, does your child look at it?   Yes   No

16. Does your child walk?   Yes   No

17. Does your child look at things you are looking at?   Yes   No

18. Does your child make unusual finger movements near his/her face?   Yes   No

19. Does your child try to attract your attention to his/her own activity?   Yes   No

20. Have you ever wondered if your child is deaf?   Yes   No

21. Does your child understand what people say?   Yes   No

22. Does your child sometimes stare at nothing or wander with no purpose?   Yes   No

23. Does your child look at your face to check your reaction when faced with   Yes   No

    something unfamiliar?

Please refer to: Robins, D., Fein, D., Barton, M., & Green, J. (2001). The Modified Checklist for Autism in Toddlers: An initial study investigating the early detection of autism and pervasive developmental disorders. Journal of Autism and Developmental Disorders, 31 (2), 131-144.

Appendix III

Child Health Record (booklet)

1 Copy submitted loose

National Medicines Information Centre

ST. JAMES'S HOSPITAL • DUBLIN 8
TEL 01-4730589 or 1850-727-727 • FAX 01-4730596 • www.nmic.ie

CONGESTIVE HEART FAILURE

☞ **Congestive heart failure is a complex clinical syndrome affecting 6-10% of people aged >65 years**

☞ **Early diagnosis and treatment reduces mortality and morbidity**

☞ **Standard treatment involves use of a diuretic, ACE inhibitor and ß-blocker**

☞ **Treatment of concomitant / underlying diseases improves outcome**

INTRODUCTION

Congestive heart failure (heart failure) constitutes a major public health problem[1]. It is estimated that 1-2% of the adult population have heart failure however, this rises to 6-10% of people aged > 65 years[2]. Heart failure is a major cause of mortality, with rates of up to 30% recorded at one year and 60-70% at five years[3]. Heart failure also negatively impacts on quality of life, in terms of the physical aspects of day-to-day life[4]. It is the leading cause of acute medical hospital admissions, accounting for at least 20% of admissions among people aged > 65 years[5]. Moreover, one third of hospitalized patients are readmitted 3-6 months after discharge[6]. This places a huge cost burden on the health service, accounting for about 2% of all health-care spending in some countries[2].
This bulletin will focus on the causes, diagnosis and contemporary management of heart failure, with particular reference to primary care.

PATHOPHYSIOLOGY OF HEART FAILURE

Heart failure comprises a complex clinical syndrome that arises as a consequence of an abnormality in cardiac structure, function, rhythm or conduction. Table 1 outlines the classification of heart failure according to clinical presentation[3]. In the early stages, following an insult to the myocardium, a series of compensatory changes take place to counteract any reduction in cardiac output. These include the activation of several neurohumoral systems, including the renin-angiotensin-aldosterone system (RAS), stimulation of the sympathetic nervous system and release of several natriuretic peptides (including B-type natriuretic peptide, BNP) in response to atrial and ventricular stretching[7]. In addition, the myocytes undergo structural change and this, together with the persisting influence of the neurohumoral hormones, results in remodeling of the damaged cardiac muscle. If these changes (which precede symptoms) are not reversed they cause considerable damage to heart function, leading to reduced performance and the development of symptoms[5]. This represents an opportunity to delay the onset of heart failure by early management of risk factors, including hypertension, diabetes and coronary artery disease[7].
In the Western world, underlying hypertension and coronary artery disease / prior myocardial infarction (MI) are the commonest causes of heart failure[8]. Among Framingham Heart Study subjects who were free of heart failure at baseline, lifetime risk for developing heart failure was doubled for both men and women with blood pressure > 160/100 versus < 140/90 mmHg[9]. Valvular heart disease, dilated cardiomyopathy (which may be genetic in up to 30% of cases) and thyroid dysfunction are also common causes of heart failure[7]. In fact almost any insult to the heart (e.g. infections, alcohol misuse, drugs) can result in heart failure[3].

Table 1: New York Heart Association (NYHA) classification of heart failure[3]

Class 1	Class II	Class III	Class IV
No limitation during normal physical activity	Slight limitation on moderate exertion	Marked limitation on minimal exertion	Breathless at rest

DIAGNOSIS OF HEART FAILURE

Diagnosis is primarily clinical, with confirmation from objective tests. Patients usually present with the symptoms of breathlessness, exercise intolerance and fatigue with/without oedema[3]. Chest X-ray will indicate the size of the heart and the degree, if any, of pulmonary congestion. A 12-lead electrocardiogram (ECG) is useful to identify ischaemic changes, prior MI, atrial fibrillation and left ventricular hypertrophy[3, 8]. Echocardiography is an invaluable tool to determine the type and severity (in terms of ejection fraction) of heart failure.
Heart failure is divided into 2 main types: systolic dysfunction and diastolic dysfunction. **Systolic dysfunction** occurs in up to 70% of patients; it is characterized by left ventricular dilatation, decreased ejection fraction and cardiac output and is the result of volume overload[8]. In addition to the classical symptoms, patients may also have mitral regurgitation. On echocardiography, the heart typically shows an ejection fraction of <40%, myocardial hypertrophy and dilated chambers.
Diastolic dysfunction is estimated to occur in 20-50% of heart failure patients. Patients have the classical symptoms of heart failure; however, the heart shows a normal ejection fraction on echocardiography and although there may be evidence of ventricular hypertrophy, there is usually no evidence of ventricular dilatation. The reduced cardiac output is due to abnormal relaxation (diastole), resulting in inadequate filling of the ventricles, especially during exercise[5]. Diastolic heart failure should be considered if a patient presents with classical symptoms, in the presence of a normal ejection fraction on echocardiography[2]. The following types of patients are at increased risk of diastolic heart failure: older females, patients with hypertension, obesity, diabetes or sleep

apnoea[5]. The differential diagnosis is important, since it has been shown that treating concomitant diseases such as hypertension aggressively improves prognosis significantly in diastolic heart failure[10]. If in doubt, the patient should be referred for specialist review[11].

Several studies[12] have shown that B-type natriuretic peptide (BNP) can be a useful tool in the differential diagnosis of patients with breathlessness; the primary role of BNP measurement in clinical practice is as a "rule out" test to exclude significant cardiac disease as normal BNP levels make a diagnosis of heart failure unlikely[13].

MANAGEMENT OF HEART FAILURE

The aims of treating heart failure are to improve the patient's symptoms, to avoid hospitalisation and to prolong life[2]. This involves non-pharmacologic and pharmacologic management options.

NON-PHARMACOLOGIC MANAGEMENT

Heart failure is a chronic condition that requires lifelong management. Patients and their families should be advised on the following since these are common causes of hospitalization and/or a worse prognosis in heart failure patients[14]:

Lifestyle modifications: these include smoking cessation, diet (including salt restriction to < 4g/day and weight reduction if overweight), monitoring of fluid intake (to balance intake and output with diuretic therapy) and the importance of regular exercise (especially in stable patients). Recommendations for exercise training programmes in patients with NYHA II-III heart failure have been published by the European Society of Cardiology[15].

Weight monitoring: patients should be advised to weigh themselves on a regular basis and in the case of any sudden unexpected weight gain of > 2kg in 3 days to either report it or increase their dose of diuretic as agreed with their physician[13].

Adherence to medication regimen: this is especially important when patients become asymptomatic.

Avoidance of certain medications: these include non-steroidal anti-inflammatory drugs (negative effect on renal function leading to fluid retention), tricyclic anti-depressants (cardio-toxic), lithium (risk of toxicity with sodium depletion) and corticosteroids (fluid retention, hypertension)[13].

In addition, patients should be advised to seek **early treatment of acute chest infections** and receive **regular immunization against influenza and pneumococcal infections** in order to prevent respiratory infection-related hospitalization[16].

PHARMACOLOGIC MANAGEMENT

The aims of pharmacologic management are to improve the patient's symptoms and to delay or prevent the structural damage, as described previously. **The recommended standard drug treatments are diuretics, angiotensin-converting enzyme inhibitors (ACEIs) and ß-blockers.** It is important to note that nearly all the evidence base for use of these drugs comes from studies undertaken in patients with heart failure due to systolic dysfunction[10].

DIURETICS – Background: Diuretic treatment results in rapid improvement in symptoms and increased exercise tolerance in more than two-thirds of patients with congestive heart failure[17]. However, no studies on their effect on mortality have been undertaken (with the exception of spironolactone), therefore they are not recommended for monotherapy in heart failure but rather should be used in association with an ACEI and ß-blocker[18]. Loop diuretics are usually the diuretic of first choice as they result in urinary excretion of up to 25% of the filtered load of sodium[19]; there are no apparent differences in efficacy between the various loop diuretics[17]. Restriction of fluid to < 1 litre per day may be recommended in refractory patients to relieve fluid retention[18]. Thiazides are less potent diuretics (excretion of approximately 5% of the filtered sodium load), but they may be useful as initial therapy in patients with mild heart failure and concomitant hypertension[17]. Thiazides may also be added to loop diuretic therapy, under careful supervision, to improve symptomatic relief.

SPIRONOLACTONE is a diuretic that acts via aldosterone antagonism[20]. It was reported to reduce mortality in patients with severe heart failure from 46% to 35% over a 2-year period of review, when used as "add-on" therapy to existing diuretic, ACEI and ß-blocker therapy[21]. Monitoring of plasma potassium is especially important due to the risk of hyperkalaemia, especially when administered with ACEI or angiotensin receptor blocker (ARB), or in patients with renal dysfunction. Spironolactone is also known to cause gynaecomastia in male patients. The newer aldosterone antagonist eplerenone has also shown benefit in patients with severe heart failure when used in combination therapy[22], and has a better safety profile than spironolactone.

Practical Advice: Table 2 lists the commonly used diuretics and their recommended doses. In general, treatment should be initiated at low dosage and up-titrated according to response. It is important to remember that the dose of diuretic may need to be reduced once the patient is on optimum ACEI therapy.

Hypokalaemia is uncommon as it is usually counteracted by the co-administration of an ACEI. However, it is recommended that plasma potassium monitoring be undertaken in heart failure patients in the initial stages of treatment, when increasing the dose and in those patients also taking digoxin, due to the risk of toxicity in the presence of hypokalaemia[17]. The concomitant use of NSAIDs with loop diuretics should be avoided as they may counteract the effects of the diuretic and worsen renal function. These effects are especially likely in the older patient, where heart failure is more prevalent.

As use of **aldosterone antagonists** is reserved for NYHA class III or IV with severe symptoms, these patients will usually be under specialist care. However, it is important to ensure that plasma potassium and creatinine levels are regularly checked.

Table 2: Commonly prescribed diuretic agents in Ireland*

Drug Name	Drug type	Recommended Initial Dose[7,13,23]	Maximum Daily Dose[7,13,23]
Furosemide	Loop diuretic	20-40mg once-twice daily	600mg**
Bumetanide	Loop diuretic	0.5-1mg once-twice daily	5-10mg***
Bendroflumethiazide	Thiazide	2.5mg daily	10mg
Spironolactone****	Aldosterone antagonist	12.5-25 (50mg if no ACEI)	50mg (100-200mg if no ACEI)

*Data from GMS diuretic prescribing figures for April 2006 from Eastern Regional Area.

** doses > 80mg with specialist supervision only   *** doses > 2mg with specialist supervision only **** specialist supervision drug

ACEIs – Background: Several large studies have shown that ACEIs decrease the rate of hospitalizations, improve symptoms and increase survival in heart failure patients[13]. A summary of the types and doses of ACEIs used in the main studies in heart failure is contained in Table 3. They are thought to exert their effect in heart failure by inhibiting the multiple pathophysiological effects of angiotensin II and decreasing the breakdown of bradykinin (which promotes vasodilatation in the vascular endothelium and causes natriuresis in the kidneys)[5]. They are recommended for use in all stages of heart failure, including asymptomatic patients, but their

effect is more marked in patients with more severe symptoms[11].

Practical Advice: Treatment should be initiated with the lowest recommended dose and gradually titrated at one to two weekly intervals to the recommended maintenance dose (see Table 3 and the Summary of Product Characteristics for individual drugs[23]). Excessive diuresis should be avoided before treatment. After the initial dose, the patient may suffer hypotension, therefore blood pressure should be monitored, especially if he/she is known to have renal dysfunction or low blood pressure. In addition, renal function, plasma electrolytes and blood pressure should be evaluated after each increase of dose until the target dose is reached. Thereafter, they should be checked at 3-6 monthly intervals. If renal function deteriorates, the ACEI should be stopped and the patient referred for specialist advice[13]. ACEIs may also cause angioedema (at any time during treatment) and dry cough occurs frequently; these adverse effects may also necessitate discontinuation of treatment and switch to ARBs[13] (see below).

Table 3: Summary of ACEIs evaluated in the main heart failure studies[13,23]

Drug Name	Recommended* Initial Dose	Recommended* Maintenance Dose
Enalapril	2.5mg daily	10mg twice daily
Lisinopril	2.5mg daily	5-20mg daily
Captopril	6.25mg three times daily	25-50mg three times daily
Ramipril	1.25-2.5mg daily	2.5-5mg twice daily
Trandolapril	1mg daily	4mg daily

Note: Other ACEIs may be authorised for heart failure in Ireland. Check individual Summaries of Product Characteristics for recommended doses.

 * as per Summary of Product Characteristics

ß-BLOCKERS – Background: ß-blockers have been evaluated in more than 20,000 patients with heart failure who participated in over 20 placebo-controlled clinical trials[7]. Results have shown that long-term treatment with ß-blockers can lessen the symptoms of heart failure, improve clinical status and enhance the patient's overall sense of well-being, as well as reducing the combined risk of death or hospitalization. ß-blockers may not all have the same efficacy[11]; Table 4 outlines the ß-blockers for whom the most clinical evidence of efficacy is available, together with the recommended dosage regimen.

Practical Advice: ß-blockers should be suitable for most patients with heart failure, provided their symptoms are stable and they don't have substantial fluid retention[5]. They should be started at a low dose and since symptoms may be exacerbated initially, heart rate, blood pressure and overall clinical status, including weight, should be closely monitored. Patients should be advised that exacerbations of heart failure symptoms may occur but are likely to be temporary. They should be told not to stop taking their medication without first consulting their physician as the symptoms can usually be managed in the short-term by adjustment of other medications such as diuretics. The dose should be slowly increased (no greater than a doubling of the previous dose, at intervals of no less than 2 weeks apart) until the recommended maximum dose/highest tolerated dose is achieved[11]. During up-titration, if patients develop worsening of symptoms, the existing dose should be halved or the dose of diuretic increased and the situation reviewed in 2 weeks. If no improvement occurs, specialist advice should be sought. ß-blockers are known to cause bradycardia and to lower blood pressure. If the patient develops bradycardia (<50 bpm) or symptomatic hypotension, the dose should be halved and the patient reviewed for the possibility of heart block. In general, it is important NOT to discontinue the ß-blocker suddenly unless absolutely necessary as there is a risk of a "rebound" increase in myocardial ischaemia[11]. If in doubt, specialist advice should be sought. Lethargy and fatigue have also been reported with use of ß-blockers and may result in a reduction of dose or prevent titration to the maximum recommended dose[20].

ß-blockers should not be used or should be used only with extreme caution[5] in the following groups of patients: patients with reactive airways disease, those with diabetes in association with frequent episodes of hypoglycaemia and those with bradyarrhythmias or heart block who do not have a pacemaker. It is likely that these patients will be under specialist care already.

Table 4: Summary of ß -blockers evaluated in the main heart failure studies[7,23]

Drug name	Recommended* Initial Dose	Recommended* Maximum Dose
Bisoprolol	1.25mg once daily	10mg once daily
Carvedilol	3.125mg twice daily	25mg twice daily
Metoprolol succinate CR**	12.5-25mg once daily	200mg once daily
Nebivolol	1.25mg	10mg once daily

Other ß-blockers may be authorised for heart failure in Ireland. Check Summary of Product Characteristics for recommended doses. * as per Summary of Product Characteristics

** not authorized in Ireland; dosage based on clinical trials data

OTHER DRUGS

ANGIOTENSIN RECEPTOR BLOCKERS (ARBs): Like ACEIs, these drugs act by inhibiting the renin-angiotensin system. They are used in the management of hypertension and more recently some ARBs have shown efficacy in terms of improved mortality and morbidity in the management of heart failure in clinical trials. Table 5 lists the ARBs authorised for heart failure treatment in Ireland. Overall, there is considerably less experience with use of ARBs in heart failure compared with ACEIs[7]. There is a difference between expert guidelines as to the current role of ARBs in the management of heart failure[24]. All guidelines agree that ARBs should be used in patients intolerant of ACEIs (e.g. due to cough, angioedema). In addition, studies have shown a modest decrease in hospitalization with ARBs used in combination with ACEIs[7]. Previously, uncertainty existed regarding the safety of combination of an ARB and a ß-blocker, but these concerns have been addressed in recent studies[13]. However, it is recommended that such combination use should be under specialist supervision[20]. The practical advice regarding initiation of dosage and monitoring of ARB usage is similar to the guidance given for ACEIs (see above).

Table 5: Angiotensin Receptors Blockers (ARBs) licensed for heart failure treatment in Ireland[23]

Drug name	Recommended* Initial Dose	Recommended* Maintenance Dose
Losartan	12.5mg once daily	50mg once daily
Candesartan	4mg once daily	32mg once daily
Valsartan	40mg twice daily	160mg twice daily

DIGOXIN: Atrial fibrillation occurs frequently in patients with heart failure, therefore many patients may receive digoxin for rhythm control[20]. The role of digoxin, which has positive inotropic activity, in the contemporary management of heart failure in patients with sinus rhythm is more controversial[24]. The DIG study[25], involving more than 6,000 patients with normal sinus rhythm heart failure, with an average follow-up of 37 months, showed no significant benefit in terms of mortality for digoxin over placebo. However, there was a significant reduction in hospitalizations both overall and for worsening heart failure. Current guidelines give conflicting advice regarding the role of digoxin in heart failure patients with normal sinus rhythm[7,13]. However, it does appear to have a potential role in patients in normal sinus rhythm who have worsening or severe heart failure due to left ventricular systolic dysfunction, despite treatment with ACEI, ß-blocker and diuretic therapy[11]. Such usage should be under specialist supervision[20] and plasma potassium levels must be monitored regularly to avoid toxicity due to hypokalaemia.

OTHER PHARMACOLOGIC AGENTS[13]: Vasodilator agents (e.g. hydralazine, isosorbide dinitrate) have no specific role in the management of heart failure although they may be used as adjunctive therapy for concomitant angina. However, studies have shown that a combination of hydralazine and isosorbide dinitrate may be beneficial when added to standard therapy in African-American patients with moderate to severe heart failure[26]. In general, calcium antagonists are not recommended in heart failure. In particular, diltiazem and verapamil-type calcium antagonists are not recommended in the presence of systolic dysfunction and are contraindicated with the use of ß-blockers. Felodipine and amlodipine may offer a safe alternative for the treatment of concomitant hypertension or angina not controlled by nitrates and ß-blockers. Amiodarone may be used for the prevention of ventricular arrhythmias in high-risk patients with heart failure[7], but only under specialist supervision[27].

IMPLANTABLE DEVICES may be used for the management of specific types of heart failure, including refractory patients or those at high risk of sudden death. In addition to standard pacemakers, **cardiac resynchronisation therapy (CRT)** is a specific pacemaker-based approach used to improve ventricular synchrony and overcome conduction defects in patients with a wide QRS complex on ECG and severe systolic dysfunction. Although symptomatic improvements have been reported, CRT has not been shown to enhance survival[5]. **Implantable cardioverter defibrillators (ICD)** may be used for patients who have survived cardiac arrest and/or have sustained ventricular tachycardia, which is either poorly tolerated or is worsening ventricular function[13].

THE MANAGEMENT OF DIASTOLIC HEART FAILURE

There are little objective data to guide the therapy of patients with diastolic heart failure[10]. These patients often present with breathlessness but with none of the other signs and symptoms of heart disease. It is recommended that where this type of heart failure is suspected the patient should be referred for specialist diagnosis and treatment[11]. In the absence of controlled clinical trials, management is based on control of physiological factors (blood pressure, heart rate, blood volume and myocardial ischaemia) that are known to exert important effects on ventricular relaxation (i.e. diastole)[7]. As mentioned previously, these patients are frequently older females with concomitant illnesses such as hypertension and diabetes mellitus, therefore optimal management of these underlying conditions results in symptomatic improvement and improved survival prospects[10].

MANAGEMENT OF HEART FAILURE IN GENERAL PRACTICE

Table 6 outlines the steps to be taken in the management of patients with heart failure in general practice.

Table 6. Management Outline of Heart Failure Patients in General Practice[13]

- Identify symptoms and signs of heart failure; confirm diagnosis with appropriate tests (as above)
- Assess the severity of symptoms
- Determine underlying causes and precipitating factors
- Counsel patient and relatives on non-pharmacological / lifestyle management programme and need for, and importance of adherence to, his/her therapeutic regimen
- Initiate standard therapy of diuretic, ACEI and ß-blocker (using dosing schedules outlined above)
- Identify concomitant diseases and include their treatment in the overall management programme for the individual patient
- Monitor patient's progress in terms of response to individualized drug and lifestyle management programme on a regular basis
- Seek specialist advice if patient cannot tolerate standard therapy/deteriorates while on maximum standard therapy or if uncertain about the diagnosis

SUMMARY

Heart failure is one of the commonest diseases encountered in general practice. Current guidelines recommend the use of diuretics, ACEIs, and ß-blockers (in addition to lifestyle management and control of concomitant diseases) as standard therapy for heart failure patients[7,11,13]. However, studies have shown that patients in general practice do not routinely receive these therapies[28]. This may be because the patients encountered in everyday practice are more difficult to treat than patients enrolled in clinical trials. A recent multinational EU study[29] showed that only about 56% of prescribing for heart failure management in primary care was appropriate, taking patient characteristics into account. Age, gender and co-morbidities such as chronic obstructive lung disease appeared to influence the type and combination of therapies prescribed in the patients. The authors suggest that prescribers may be unwilling to disturb the therapeutic status quo in a patient with co-morbidities, despite the evidence base supporting the benefit of the above standard therapies. Moreover, under-utilisation of the so-called standard therapies has been identified in patients with no obvious contraindications to their use[30]. This included sub-optimal dosage of ACEIs and under-prescribing of ß-blockers. While use of lower doses or monotherapy may be better than none at all[31], the evidence base for efficacy in terms of improved outcome for the patient is based on the optimum drugs and dosages used in the landmark trials.

A heart failure management programme that includes multidrug therapy allows symptomatic relief of the patient's symptoms and avoids hospitalizations; in addition, it addresses the pathophysiological process underlying the development of heart failure[32], thereby improving survival prospects.

Appendix 5: First Signs Site Map

Direct Links to Topics

[Home](#)

- [Contact Us](#)

- [Site Map](#)

- [FAQ](#)

- [Search](#)

[In Your State](#)

- [DE](#)

  o [Local Resources](#)

- [PA](#)

  o [Fact Sheet](#)

  o [Press Release](#)

  o [Local Resources](#)

- [MN](#)

  o [Fact Sheet](#)

  o [Press Release](#)

  o [Webcast Training Page](#)

  o [Local Resources](#)

- NJ

  - Press Release

  - Local Resources

- WI

- Bringing First Signs to Your State

Who We Are

- How We Began

- Why Early ID?

- Advisory Board

- Board of Directors

- Funding

- Press Center

Concerns About a Child

- Monitoring Development

- Hallmark Developmental Milestones

- If You Have Concerns

- Red Flags

- Sharing Concerns

  - Parent to Physician

  - Physician to Parent

- o [Parent to Parent](#)

- [Developmental and Behavioral Disorders](#)

  - o [Autism Spectrum Disorders](#)

  - o [Other Developmental Disorders](#)

[Screening](#)

- [Screening Guidelines](#)

- [Developmental Screening](#)

- [Audiological Screening](#)

- [Lead Screening](#)

- [Autism Screening](#)

- [Screening Tools](#)

  - o [DSM IV Criteria](#)

  - o [Screening Tools Selection Criteria](#)

  - o [Psychometric Terms](#)

  - o [Recommended Screening Tools](#)

  - o [References](#)

- [First Signs Screening Products](#)

  - o [On The Spectrum: Children and Autism Video](#)

  - o [First Signs Screening Kit](#)

  - o [First Signs Wall Chart](#)

  - o [First Signs Order Form](#)

  - o [First Signs Order Form (PDF)](#)

Diagnosis and Treatment

- Early Intervention

- Your Local School District

- Specialists

- Diagnostic Testing

- Next Steps

- Understanding Your Insurance Plan

- Treatments

Research

- Latest Research on Early Detection

- Studies Recruiting Participants

- Research Institutes and Organizations

- Doing Your Own Research

Resources

- Web Sites

  - Healthy Development

  - Special Needs

  - Screening and Referral

  - Autism Spectrum Disorders

- - Developmental and Behavioral Disorders

  - Education and Service Delivery

  - Insurance and Disability Planning

  - Treatments

  - Family Support

  - Web Sites for Children

  - Resources in First Signs States

- Books and Literature

  - Healthy Development

  - Special Needs

  - Autism Spectrum Disorders

  - Educational Interventions

  - Treatments

  - Books for Children

- Videos and DVDs

- Products and Services

Articles

- Articles

- Guest Columns

- Book Reviews

Products

- [On The Spectrum: Children and Autism Video](#)

- [First Signs Screening Kit](#)

- [First Signs Wall Chart: Key Milestones for Social, Emotional and Communication Development](#)

- [First Signs Fundraiser Bracelet](#)

- [First Signs Order Form](#)

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[Back to top](#)

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i