Best Practice Guidelines for Parental Involvement in Monitoring and Assessing Young Children
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Introduction

Monitoring and assessing children’s development and wellbeing during the early years is an important function of early childhood services. These best practice guidelines look at the research evidence and best practice regarding how this function can be conducted most effectively, and what role parents should play.

For the purpose of this document, the term parent is used to mean a parent or primary caregiver.

Background

In Victoria, there are well-established protocols and services for supporting young children and their families and for monitoring their health and development. These take the form of a dedicated service – the Maternal and Child Health Nursing (MCHN) service – and a schedule of 10 key ages and stages visits over the first 42 months of the child’s life. However, while take-up of this service is excellent over the early visits (over 90 per cent for the first four), it falls away after that (to 58 per cent for the final visit at 3.5 years) (MCH Services Annual Report 2005–2006). This drop-off in service usage compromises the ability of MCH nurses to help identify children with emerging health and developmental needs, and families with parenting and other concerns.

The reasons for this drop-off in service usage are complex, but include the changed circumstances in which families are now raising children, especially the greater involvement of parents in the workforce. While the existing MCHN protocols (Office for Children, 2006) and best practice guidelines (Meisels & Atkins-Burnett, 2000; Neiswoth & Bagnato, 2000) both suggest that parents should always be present when children are seen, there are some circumstances where this is difficult to arrange. There is also a small percentage of families whom service providers find difficult to engage with their services at any stage (Carbone et al., 2004).

Why the issue is important

Research over the past few decades has demonstrated the importance of the early years in laying the foundation for later health, development and wellbeing (Centre for Community Child Health, 2006a). Research has also shown:

- that there are various forms of early intervention that are effective in off-setting the effects of adverse early experiences and environments (Anderson et al., 2003; Karoly et al., 2005; Shonkoff & Phillips, 2000)
- that these programs are highly cost effective in the long term (Isaacs, 2007; Heckman & Masterov, 2004; Rolnik & Grunewald, 2003), and
- that the earlier children are involved in such programs the more effective they are (Galinsky, 2006).

For children and families to access intervention and support services early, there needs to be an efficient system for identifying developmental concerns about children and for prompt referral to appropriate intervention and family support programs.
Definitions

The terms screening, surveillance and assessment are sometimes used interchangeably but describe quite distinct functions.

**Screening**

involves the use of specific tests or examinations to identify those people in a population who are likely to have a particular condition or disorder (Baird et al., 2001; Oberklaid et al., 2002). Screening tests are not diagnostic, but sort out those who are likely to have the condition from those who are likely not to. They are performed at a particular point in time – in the case of young children, usually shortly after birth – and are used for conditions that can be measured on a single parameter with a clear cut-off point (e.g. PKU, congenital hypothyroidism).

**Surveillance**

is the ongoing and systematic collection of information relating to particular disorders or conditions over time by an integrated service system (Dworkin, 2000; Lamont-Herps and Robson, 2001; Oberklaid et al., 2002). Again, surveillance procedures are not diagnostic, but identify those who need further assessment. Surveillance procedures are performed at several points in time – if a child does not meet certain criteria one or more of these times, this would indicate a higher likelihood of the child having a particular disorder or condition. Surveillance procedures are used to identify health or developmental conditions that involve multiple parameters, each of which falls on a continuum without a clear cut-off point. Such conditions include certain health issues (such as overweight / obesity) and developmental issues (delays and disabilities).

**Assessment**

involves a synthesis of findings from the history, physical and neurological examination, as well as from detailed testing using standardised instruments (Oberklaid & Efron, 2005; Meisels & Atkins-Burnett, 2000). While the initial referral for a child suspected of having developmental delay is often to a paediatrician, detailed assessment of development is usually undertaken by a multidisciplinary team, and should include parents (Guralnick, 2000).

Assessment procedures are performed whenever a child has been identified through developmental surveillance as potentially having a particular condition that warrants ongoing intervention. The goal of the assessment is to develop an accurate developmental profile of the child’s current strengths and weaknesses, and any continuing risk factors. It leads to a specific intervention plan that is individualised according to the needs of the child in order to achieve the best developmental outcome (Meisels & Atkins-Burnett, 2000; Oberklaid & Efron, 2005).
What the research tells us

**Efficacy of current system in identifying children with developmental problems**

There is evidence that the current service system fails to detect all the children who need additional help (Sawyer et al., 2000; Sayal, 2006). These detection and referral failures can occur at a number of different stages. Sayal (2006) identifies four stages of help-seeking – parental perception of problems, raising concerns with primary care services, recognition of problems within primary care, and referral to or use of specialist health services – and shows how each of these can act as filters to prevent children being referred for specialist help.

One of the points at which the detection and referral system can break down is when health care providers fail to listen and take parents’ views seriously (Williams, 2005). This can occur when professionals view their ‘scientific’ knowledge and training as superior to the ‘intuitive’ knowledge of the mother. This is despite the research that shows that, when health professionals incorporate parental data, their clinical judgments increase in accuracy (Glascoe & Dworkin, 1995).

Another reason why children and families in need of help are not identified promptly is that health care providers may use inappropriate screening tools or techniques, relying unduly on clinical observation and informal checklists that lack validation and distinct cutoffs, or use screening tests with limited accuracy (Glascoe, 2005). Even when they are identified, they may not be referred to appropriate early intervention services or early childhood development programs (Glascoe, 2000; King & Glascoe, 2003).

**Efficacy of professionally administered screening tools**

There is clear evidence for the effectiveness of screening for a number of conditions, many of which are readily detectable in the neonatal period (Oberklaid et al., 2002). The conditions for which screening is effective are those in which the child either ‘has’ or ‘does not have’ a disease or condition, and that if one has, it can and will be treated effectively.

However, screening is not effective for conditions for which early detection and intervention may seem a useful goal, but for which no such distinction can readily be made, ie. where there is considerable difficulty in categorising children as ‘having’ or ‘not having’ the condition. Typical of this are the diverse problems that may occur in child development (including language) and behaviour. Many developmental screening tools have been developed for the purpose of making these distinctions, but none reach acceptable levels of sensitivity and specificity, and therefore could not be used as part of universal developmental screening programs – either for global development or for specific developmental areas (Oberklaid et al., 2002).

**Evidence of efficacy of parent administered tools**

Are parents any better than professionals at judging their children’s development? Parents can provide two broad types of clinical information about their children’s development and behavioural status (Dworkin, 2000; Glascoe & Dworkin, 1995):

They can share their concerns and they can describe their children’s past and current functioning. Parent’s concerns for their children’s development had been shown to be accurate indicators of true developmental problems, regardless of differences in the parents’ education and child-rearing experience (Squires et al., 2002; Dworkin, 2000; Glascoe, 2000). As Hall and Elliman (2003) have noted, parents are often the first to suspect their child might have a developmental problem, and their concerns should always be taken seriously: ‘They may not understand the significance of their observations but they are very efficient at detecting that something is amiss’ (p. 133).
Parents have also been found to be reasonably accurate in providing estimations of their children’s developmental level (Dinnebeil & Rule, 1994), although they are generally more accurate about children’s current development than their future functioning, and their recall of past developmental milestones is notoriously unreliable (Dworkin, 2000).

On the basis of this evidence, there has been a growing move to incorporate parental reports into developmental surveillance procedures (Bricker et al., 2004; Glascoe, 1997a, 1998, 1999; Squires, 1996). Research suggests that one of the most effective ways of detecting developmental delay in young children is via parent report (Glascoe, 2005; Oberklaid & Effron, 2005), and that using parental reports of development is an efficient and effective way of selecting out children who require a more detailed assessment and/or referral. In addition, such practices are consistent with family-centred approaches to working with parents. Family-centred practice (Moore & Larkin, 2006) and family-centred care (American Academy of Pediatrics Committee on Hospital Care, 2003) are now recognised as the cornerstone of effective work with parents and families.

A number of proven parent-completed developmental surveillance tools have been developed. Those that have been adapted for or found to be effective in Australian conditions include the Parents’ Evaluation of Developmental Status (PEDS) (Glascoe, 1997b, 1998), the Ages and Stages Questionnaire (ASQ) (Bricker and Squires, 1999), and the Ages and Stages Questionnaires: Social-Emotional (ASQ:SE) (Squires et al., 2002).

These tools are seen as having a number of advantages:

- Parents possess a wealth of information about their children that is not accessible to professionals during a brief examination or visit (Squires, 1996).
- Parent’s knowledge about child development in general and their own child’s development in particular may be enhanced by completing questionnaires (Squires, 1996).
- Parental involvement in developmental surveillance is empowering and consistent with family-centred practice (Squires, 1996).
- Although many surveillance tools rely on direct measurement of children’s skills, such measurement is not always practicable in clinic settings, where children may be too distracted or too ill to fully demonstrate their skills. Surveillance measures that rely on parental reports are especially helpful because they eliminate the need for obtaining children’s cooperation and effort (Glascoe & Dworkin, 1995).
- They provide a more thorough and extensive sampling of children’s skills than what can be typically obtained with direct facilitation measures (Glascoe & Dworkin, 1995).
- They can be administered in a number of different ways (face-to-face interviews, telephone interviews, taken home by parents and completed in preparation for a second appointment, self-administered in waiting rooms, etc.) (Glascoe & Dworkin, 1995).
- They provide a structured way of asking parents about their concerns (Squires, 1996). Wright and Oberklaid (2004) suggest that one of the great strengths of such a tool as the PEDS is that it facilitates a dialogue with parents about their child. This dialogue allows discussion with parents about areas that are of concern whether or not a significant problem is identified. In addition, this dialogue fits very well with the broader family-centred approach to practice in primary care.
- They are cost-effective (Glascoe et al., 1997; Squires, 1996).
Best practice guidelines

Over the last decade or so, there has been a broadening of our understanding of what paediatric care and developmental monitoring should involve. There are several dimensions to this change:

- There has been a shift from a relatively narrow focus on health monitoring to a broader notion of monitoring development and wellbeing (Dworkin, 2000; Zuckerman & Parker, 2002).
- There has been shift from a health treatment model to a focus on prevention and health promotion (Department of Human Services, 2004; Green & Palfrey, 2002; Zuckerman et al., 2004).
- The nature of the relationship between professionals and parents has altered, with a much greater emphasis on family centred practices (Moore & Larkin, 2006), parent / professional partnerships (American Academy of Pediatrics, 2003), and an expanded role for parents in monitoring their own children's health and development (Glascoe & Dworkin, 1995).

The active involvement of parents as partners with health professionals in the developmental surveillance and assessment of their children is now recommended by all key authorities (e.g. American Academy of Pediatrics, 2003; Green & Palfrey, 2002; Oberklaid et al., 2002). For instance, in the assessment approach recommended by Greenspan et al. (1996), assessment is seen as a collaborative process, involving ongoing collaboration between clinicians and parents in understanding the child and family. This group also recommended that young children should never be separated during the assessment from their parents or caregivers.

The active involvement of parents in the assessment of young children with developmental disabilities is a well-established principle in early childhood intervention services (Boone & Crais, 2002; Neisworth & Bagnato, 2000; Popper, 1996). Miller & Hanft (1999) see such partnerships with families as the cornerstone of developmental assessments.

The ability of health professionals to involve parents of young children in developmental surveillance is critically dependent upon the nature of the relationship they develop, not just their professional knowledge and skills (Moore, 2006). Developing positive relationships depends in turn upon two sets of skills: communication / helping skills and family-centred care / partnerships skills.

- Communication and helping skills
  There is good evidence that the quality of health professionals' communication and helping skills have significant effects on patient satisfaction and compliance as well as actual health outcomes (Braun et al., 2006; Di Blasi et al., 2001; Nobile & Drotar, 2003; Stewart et al., 1999).

- Family-centred care and partnership skills
  The second set of skills essential for positive relationships with parents are skills in establishing partnerships with parents and in delivering family-centred care (Centre for Community Child Health, 2007). The principles of family-centred care (American Academy of Pediatrics Committee on Hospital Care, 2003; Shelton & Stepnek, 1994) and patient-centred care (Little et al., 2001; Stewart, 2001) are well established. Family-centered care is based upon collaboration among patients, families, physicians, nurses, and other professionals for the planning, delivery, and evaluation of health care as well as in the education of health care professionals (American Academy of Pediatrics Committee on Hospital Care, 2003). Health care based upon such principles has been shown to be beneficial to patients.

Based on various service models and recommendations developed by Glascoe (2000), Oberklaid & Efron (2005) and Oberklaid et al. (2002), the following three-stage model of developmental surveillance for young children is recommended:

- **Stage 1: Primary surveillance of all children**
  conducted by parents and professionals in partnership, using validated parent-completed developmental surveillance scales / tools (e.g. Peds, Ages and Stages)
No single professional group is ideally suited or unsuited to this task: multiple perspectives from parents and a range of professionals are needed (Meisels & Atkins-Burnett, 2000), and all professionals working with children and parents should engage the parents actively in discussions regarding their children.

- **Stage 2: Secondary developmental screening of children about whom the parents have significant concerns**
  conducted by primary care professionals with the help of parents, using validated developmental scales / tools (e.g. Brigance Screens (Brigance & Glascoe, 2002; Glascoe, 2002)

- **Stage 3: Full specialist assessment of children who fail the secondary screening**
  conducted by professionals (individuals or teams) using specialised tests.

Regarding the use of specialised tests, it should be noted that there have been challenges to the use of traditional formal psychometric assessment approaches with young children (Bagnato & Yeh-Ho, 2006; Meisels & Atkins-Burnett, 2000). Instead, it is argued that more appropriate assessment practices for this age group should involve authentic assessment strategies (Bagnato, 2007; Neisworth & Bagnato, 2004).

Oberklaid, Wake, Harris, Hesketh & Wright (2002) conclude their review of screening and surveillance methods and issues with the following recommendation:

‘For development and behaviour, we recommend a conceptual move away from tests, check lists, and especially categorising children into pass/fail groups towards the concept that most children and families would benefit from ongoing contact with a universal system that is responsive to their needs. Ideally parent concerns and risk factors would be systematically elicited and addressed; a range of graded interventions offered in context; longitudinal follow-up would occur to take into account the changing nature of development and risk and protective factors; seamless referral and follow-up systems would be put into place in community networks; and the whole system would be underpinned by a system of quality assurance to ensure that structures and processes are consistent with contemporary knowledge.’

In addition, services need to become more effective at catering for the needs of all children and families (Centre for Community Child Health, 2006b). Australian studies (Carbone et al., 2004; Walker, 2004) suggest that universal early childhood services are not as accessible or inclusive as they need to be.

- **Explore ways of making universal services more inclusive**
  This could involve ensuring that such services are affordable, well publicised, and geographically accessible; providing outreach and support with transport; providing a family-friendly and culturally inclusive physical environment; employing skilled and responsive staff working from a family-centred, culturally sensitive perspective; promoting social connectedness through informal supports; and establishing strong reciprocal links with other relevant services (both universal and specialist) (Carbone et al., 2004).

- **Make special efforts to reach the marginalised groups who make poor use of services, universal or otherwise**
  (Carbone et al., 2004; Ghate & Hazel, 2002; Hogue et al., 1999; and Weeks, 2004). This includes understanding what factors contribute to families not maintaining contact with services (Attride-Stirling et al., 2004). Among the most critical factors is the worker’s ability to establish a positive, non-judgmental relationships with all children and parents (Attride-Stirling et al., 2001), and to proactively engage and sensitively follow-up vulnerable children and parents who are at risk of ‘dropping out’ (Carbone et al., 2004). Weeks (2004) also stresses the importance of the physical environment in service delivery, and identifies ways of creating services that are comfortable, safe, friendly and attractive for people who are facing family difficulties in attending.
What the implications of the research are

- Developmental surveillance is now seen as focusing on more than health, nutrition and physical development to include children's general development and wellbeing.
- This broadened conception of what developmental surveillance entails requires new skills of MCHNs and a change in the nature of the relationship between professionals and parents towards a partnership model.
- Early identification of young children with health and developmental problems is vital if we are to get better outcomes for all young children and families.
- If detection rates are to improve, three steps are needed: increasing the take-up of MCHN services, ensuring that appropriate developmental surveillance tools and procedures are used, and involving all parents as active partners in monitoring their children's health and development.
- Effective surveillance involves taking parents' concerns and judgements seriously, engaging them as partners in monitoring their children's development, and using proven parent report tools.
- Skills needed for effective developmental surveillance include communication and helping skills as well as family-centred care / partnerships skills.
- As well as early identification, the prompt referral of children with health and developmental problems to appropriate intervention services is also vital if we are to get better outcomes for all young children and families.
- A three-stage model of developmental surveillance for young children is recommended: primary surveillance of all children, secondary developmental screening of children about whom the parents have significant concerns, and full specialist assessment of children who fail the secondary screening.

Consideration for policy and programs

- To improve the take-up of MCHN services, ways of making universal services more inclusive need to be developed, and special efforts made to reach the marginalised groups who make poor use of services.
- To ensure that appropriate developmental surveillance tools and procedures are used, appropriate guidelines for MCHN practice will need to be developed, and training in the use of proven tools and procedures provided.
- To increase the involvement of families in surveillance and assessment procedures, a variety of ways should be developed for communicating to parents the nature of the changed parent/professional role and the importance of their involvement as partners in the process.
- It will also be helpful to strengthen messages to parents about what the key ages and stages consultations are about and why they are important – importance of the early years, picking up problems early, ensuring that the system responds promptly to emerging child and family needs, and the potential role of MCHNs as a conduit to sources of help.
- Parental involvement can also be increased by providing services available at different times (e.g. after hours and Saturday mornings) and locations (e.g. early childhood centres, shopping malls).
- If referral rates are to improve, the links between MCHN services and other services will need to be strengthened, so that the MCH service becomes an integral part of a comprehensive system of child and family services and children's centres.
Best practice guidelines

- Partnerships with parents should be based on principles of family-centred care, and aim at establishing relationships that are caring, responsive and collaborative.
- In order to maximise parental involvement, service providers should provide services at various times and locations to meet the needs of their local community.
- Wherever possible, parents should be present and actively involved when their children are being seen for developmental surveillance or assessment.
- When this is not possible, other family members or caregivers who know the child well and are trusted by the parents should be present and actively participating in the surveillance / assessment process:
  - Whenever parents cannot be present they must be contacted beforehand to discuss the process and obtain their views of the child, and again afterwards to discuss and confirm the conclusions.
  - When parents cannot be present, documentation of the contact made with the parent both beforehand and after the assessment should always occur.
- Proven parent-completed surveillance tools should be used to facilitate the discussion about the child’s health, development and wellbeing.
- A range of ways in which such tools can be administered should be used, including face-to-face interviews, telephone interviews, taken home by parents and completed in preparation for a second appointment, and self-administered in waiting rooms.
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