

# **INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT**

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# INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT

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# INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT

## **Introduction**

The following paper addresses three major issues for support services within the Health and Social Care industry. Firstly, the nature of person-centred support within a Quality of Life (see Appendix 3) and Rights (see Appendix 2) framework, both in the short and long-term; secondly, the implementation of evidence based practice that is generalisable, secure, and complies with legislation; and thirdly, the introduction of intelligent solutions that are easy to adopt, affordable, and that will support and enhance practice, both in the Health and Social Care industry and in many others.

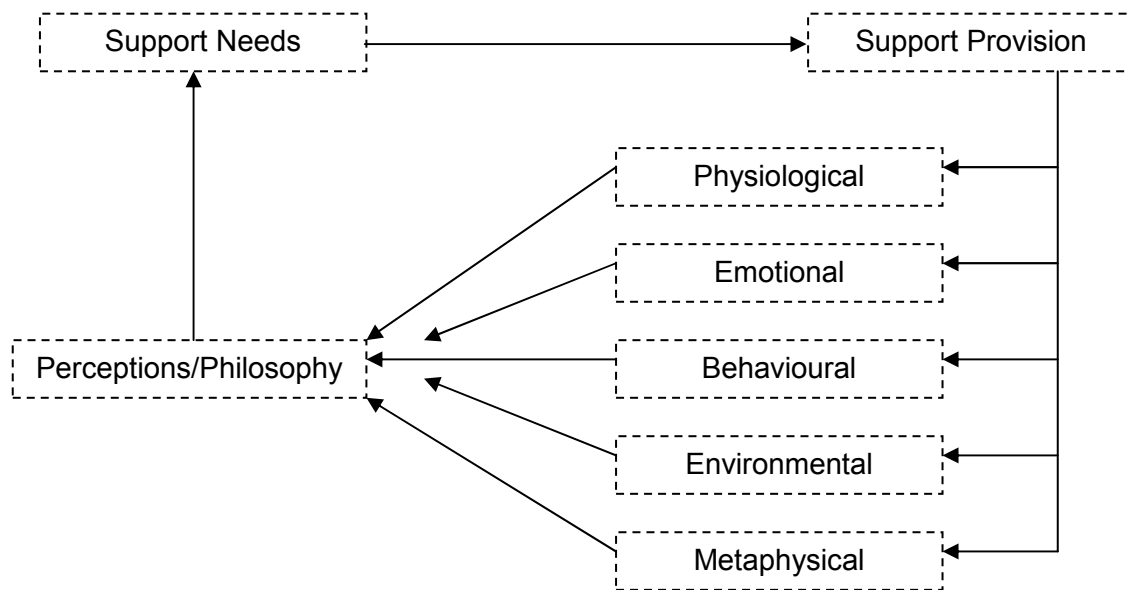
From a survey conducted across eight councils in the UK, the National Services Framework report (2003) showed that services for people with complex needs, who require specific support over extended periods, or for life, are under-developed. The needs of the individual are rarely identified or met appropriately, and in many cases, people are inappropriately placed, and/or are obliged to live a long way from home, due to the lack of local provision (NSF 2003). People with autistic spectrum disorders fall into the category of having complex needs, and in addition they often require support for life.

The heterogeneity of this population of individuals who present unique profiles, reinforces the necessity for truly person-centred support. Assessment of needs and care management should be carried out dynamically, holistically, and with an emphasis on the increasing involvement of the person in receipt of support. Too often, interventions are not based on current best practice with a lack of emphasis on self-determination and personal quality of life (Koegel 1996). Services are required that focus on empowerment, that will enhance every individual's quality of life within a framework of Rights, Independence, Choice, and Inclusion.

## **Person Centred**

'Person-centred' approaches are those which demonstrate the concern for and responsiveness to the way the person functions. The focal points of a) general support requirements, and b) specific individualised requirements, create a very complex web of service design facets. The dynamics of this have only really begun to be understood over the last thirty to forty years with the rise in de-institutionalisation and a move away from purely medical forms of intervention for the population of vulnerable individuals who have complex needs. The interpretation of 'Person-centredness' is highly subjective and is reflected in how organisations provide for each unique individual, which can vary tremendously across organisational cultures. This complex approach extends far beyond the simple environmental provision (see Fig 1) that addresses the range of activities and/or personal possessions for the person, although these are also necessary and important. It is also about the way the service structures itself to meet individual needs, as a whole.

**Figure 1: Needs and Provision**



The varied and changing needs of persons with complex support requirements, oblige service providers to develop processes of person-centred planning, within a Quality of Life (see Appendix 3) ,and a Rights (see Appendix 2) framework. These processes should also include advocacy/self-advocacy, and should be evaluative and critical. Self-determination to the maximum possible, or having someone safeguard rights, is an integral part of being seen as a valued person. Having choice and making one's own decisions are considered to be part of basic human rights and the presence of a disability is not regarded as an obstacle to those rights within the EU (UN 1988). However, in practice, there are many situations in which others are required to act as advocates on behalf of people who may not be able to advocate for themselves. Where there is no advocacy there are increased risks of abuse and potential denial of fundamental and basic human rights. Personal preferences on where to live, which activities to engage in, and with whom to spend time are viewed as entitlements within European societies, and where people are not empowered to establish these rights then what is chosen on their behalf may not lead to good quality of life (BPA 2001).

Service provision that addresses the issues of being person-centred and holistic depends upon approaches that are flexible, reflective and reflexive, with practical strategies that facilitate continuous updating. Where this type of service exists, its very nature calls for the accommodation of endless diversity, thus causing a range of service permutations to emerge, generating evolving repertoires of knowledge based on experiential learning. Realistically, this knowledge remains the domain of those who are actively involved and/or part of the process, and, unless this valuable type of knowledge is adequately recorded, stored and made accessible to others, then there is a real risk that it will be lost. Sadly, current experience and expertise tend to be contained within organisations or individuals, and these are often localised and segregated through, in some cases, geographical isolation, but, in most cases, inadequate mechanisms for sharing the information. The consequence of this is that a great deal of practice is carried out 'blindly' without access to reliable evidence from other practitioners.

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There are no available figures on the costs of trial and error practice, or how much time and effort is spent reinventing the wheel. In 2000, the costs for the care provision in the UK for people with Autistic Spectrum Disorders were estimated at £1 billion per year. The additional lifetime costs for one person with autism and associated learning disabilities was estimated at £2.4 million, while for people with High Functioning Autism (HFA) or Asperger's syndrome (AS) additional lifetime costs were £0.5 million. ( Knapp & Jarbrink, 2000). It is estimated that the costs of care provision for the 210,000 people with Severe Learning Disabilities, and the 1.2 million people with a Mild or Moderate Learning Disability, in England alone come to £3 billion per annum ([www.dh.gov.uk](http://www.dh.gov.uk)).

The process of support design becomes more complex where symptom presentation is varied within specific groups, for example: psychiatric diagnostic development in autism, HFA and ASDs (Klin et al, 2000; Klin and Volkmar, 2000). The indicators here suggest that differential diagnosis should be adopted for these individuals. However, the actual *practice* of delivering support based on this premise also requires investigation empirically as to what the resultant differential service delivery ought to consist of, and how differential delivery of lifestyle support and management can be introduced and implemented, and what costs would be incurred.

How a person's needs are assessed generally dictates what support is recommended. In this climate of uncertainty as to what type of support is appropriate and which interventions will enable and empower an individual to develop to a less dependent state, strategies that identify the most efficacious and efficient support network are desperately needed. The dilemma is how to design solutions suitable for generalised application across a wide range of services, which are able to accommodate the changing needs of each individual, both in the short and long-term, and that can also be validated.

For instance, ASDs are complex and multifaceted, and the options for intervention are highly varied and subject to little or no analytic processes. Anecdotal evidence alone on the efficacy of services or interventions is not sufficient for validation and, so far, systematic exploration of the value of long term practice is rare, partly because of the difficulty in defining what criteria comprise quality of life, and partly because of the philosophical orientation of medically biased diagnostic-prescriptive intervention practice. Where studies have been conducted, there is real need for consistency of methodology and measures across research so that results of one study can be more readily compared with that of another in a form of meta-analysis (Jordan 1999).

Currently, the drive for practice to be based on evidence has never been stronger, but there exists confusion as to what the delivery of 'evidence based practice' means to both the individual and to the care providers, and this is influenced by the nature of their roles. Finding an equitable way forward that addresses this multiplicity is highly complex.

### **The Nature of Evidence**

For practitioners in the health industry evidence is drawn from a variety of sources which broadly relate to 'evidence-based health care', 'research', and 'critical appraisal'. However these terms mean different things to different people. During the survey carried out by Douglas and Greenalgh, 2001, the doctors who were interviewed, regarded 'research evidence' as that drawn from clinical trials (preferably randomised and controlled), designed and conducted on someone else's patients and offering a

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generalisable message to a wide range of clinical situations both now and in the future. In contrast, nurses saw 'research evidence' as including local, qualitative and sometimes anecdotal information collected on one's own patients and serving primarily or exclusively to inform one's own current practice (Douglas & Greenhalgh 2001).

In reality, evidence, in the form of raw data, can be drawn from all of these practical aspects of identified support needs and care procedures, as well as the personal details of individuals.

Data can be drawn from:

- Case notes
- Case study documents (policy and procedural guidelines)
- Archival records
- Narratives (client narratives)
- Recorded Interviews
- Results from clinical studies
- Participant observations
- Artefacts (training courses, accreditation checklists, mission statements)

The methods by which evidence is currently collected, stored and accessed create some frustration for practitioners. The variety of new electronic systems, designed to resolve data management problems, tend to present people involved in primary care with both information overload and an excessive pace of change in their clinical practice. The range of information that is of potential relevance to primary care is huge, but the time available to spend on accessing and digesting it is perceived to be ever diminishing (Douglas & Greenhalgh 2001). The amounts of training needed, over and above the normal line of duty, to implement new evidence based practice, results in impossibly overburdened workloads. What is more, there is such disparity between methods, that staff, having completed their training, find it difficult to transfer their newly acquired skills.

The plethora of training in Evidence Based Practice that is currently available to practitioners is corroboration of how important this field has become. However, a certain amount of confusion surrounds existing training courses due to the terminology they contain which can be interpreted differently. For instance, the terms 'evidence-based medicine', 'evidence-based nursing', 'clinical effectiveness', 'research awareness', and 'research appreciation' are terms which are used interchangeably and inconsistently within course material and advertising. (Douglas & Greenhalgh 2001).

For practice to be based effectively on evidence, data collection techniques must be unobtrusively embedded in the practice procedures, thus enabling practitioners to carry out their roles with as little disruption as possible, whilst continuing to support the accumulation of reliable evidence. There are a number of electronic systems which provide online forms and data management, which offer substantial time saving in recording and storing information. This is preferable to paper systems which often incur repetitious duplication of information and always present a problem with storage and

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retrieval. However, there are additional significant areas for consideration, such as the safe and secure handling and management of sensitive information, areas now becoming critical to safe operation as identity theft and fraud become more prevalent.

This situation indicates a real need for solutions that are designed to address each of these areas, without imposing substantive changes in practice, or in extensive hardware/software updates, without introducing highly complex systems of operation, without necessitating extensive training, and without incurring exorbitant costs.

### **Data Management, Confidentiality and Compliance**

Compliance legislation for Health and Social Care provision in the UK not only demands adherence to the Data Protection Act 1988 and the Freedom of Information Act, etc. but also requires secure storage of records up to, and in some cases in excess of, 70 years, whilst ensuring instant access at any given moment.

Considerable progress has already been made in the field of secure data management. For example, it is now possible to create secure 'communities' where secure data transfer, recording, and retrieval under robust system protection have become possible, allowing secure links across organisational intranets and (completely securely) via the internet, thus creating a wider secure community. The 'community' is able to provide secure mechanisms for creating, storing, updating and accessing files and other forms of electronic data, and enabling people, who have had their identity checked and confirmed to share information quickly and easily without risks arising from infiltration, corruption or repudiation.

This process involves online access where the connection between the browser and the server is Single Socket Layer (SSL) secured, as used in internet banking. Data stored on the server is encrypted and tamper sealed and can only be accessed through the browser application. Where data is required to be shared securely between various users the method of accessing the data is determined by the recipients. Where information is gathered on a specific individual the data is managed by individuals, each of whom have a designated role and who have been validated for that particular secure level of access.

This type of system accommodates areas of service where immediate access to evidence is essential yet sensitive. For instance, when GPs need to obtain robust evidence quickly in the clinical situation, or at least on the same day as a clinical encounter, they are able to reflect on their practice, whilst still complying with legislation. This illustrates that the development of a secure solution for data processing and management is required for every single practice procedure relating to Health and Social Care service delivery. Sensitive information, particularly where complex needs and long-term support are involved, must be rigorously protected and secured. Furthermore, such solutions, used in conjunction across secure communities, accumulate a comprehensive resource of evidence to critically inform further practice.

One common, yet seemingly impossible goal is the standardisation of secure data collection and management, with minimal training, and, importantly, without compromising individualised content. Each solution, therefore, must be tailored to existing practice procedures that are already familiar to the practitioner, so that the

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amount of change to be embraced is barely noticeable. So, when the GP needs to record and access clinical information quickly, the solution must perform those functions without disrupting practice procedures.

As solutions are being tailored to existing practice and procedures, familiarity eases the pain of introduction. Whilst assuring information management complies with the current legislation, the practitioner is able to record and access clinical information with ease, and with minimal disruption to current procedures.

### **Practice Procedures and Intelligent Solutions**

Organisational structures can generally be broken down into roles, procedures and policies, thus producing seemingly discrete areas of responsibility relating to service provision. The analysis of role combined with procedure creates an opportunity to design applications that facilitate smooth operation and enhance outcomes. For instance: the type of procedures that involve groups of people in decision making are able to be enhanced and supported by electronic applications with intelligent algorithms embedded within them; evaluative procedures such as assessments can also be supported in this way; in fact, any recording process can be significantly augmented too.

It should be emphasised here that at no time should the human element be excluded or lost, machines cannot be substituted for personnel. However, the incorporation of these methods of collecting and processing data into everyday procedures has the advantage of yielding evidence that informs practice, without compromising the individual rights of the person and/or impeding the process of care.

The challenge involves the extensive task of amalgamating electronic applications with person-centred support processes to create intelligent solutions. This amalgamation has to be designed in such a way that will create provisions of service that can be applied across varying populations, whilst accommodating all their inherent diverse needs, procedures, and applications, and whilst encompassing a range of perspectives from the global and cultural to the intra-personal.

The initial stage involves the identification of each element that comprises person-centred support. This reveals a wide range of service procedures, such as risk assessment, intervention planning, accident and incident recording, care planning, to name but a few. The deconstruction of each of these procedures exposes the essential detail that must be incorporated into the electronic application. The intelligent algorithms are linked to the outcomes or function of the practice procedures, and these are then embedded in the procedure during re-construction. The solutions are designed to augment the performance of the organisation's defined roles with additional functions, whilst securely processing data.

The next stage is the input and storage of data that derives from implementing the range of procedures. The input comes from a dynamic network of interdependent links. This dynamic linkage of data and the constant exchange of information between data points can be conceptualised as 'rhizomatic' in nature, and allows for spontaneous additional data points to emerge randomly (Deleuze & Guattari 1987), thus continuously allowing for new measures to be identified and incorporated.

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The secure storage of this critical evidence must be implemented in a manner that offers easy access to those with the need and right to know the relevant information. This requires a catholic approach to analysis to be incorporated into the intelligent algorithms, to ensure the inclusion of a) a range of levels of analysis, from societal to intrapersonal, and b) all factors influencing the development of person-centred care. A system such as this, which is able to identify and incorporate the detail in service procedures, and that can also perform intelligent analyses in an accumulative fashion can be described as 'learning'. The rhizomatic nature of data input links and the cross-cultural facility includes such diversity that the potential to predict is a strong possibility. The technical underpinning of this type of development, however, is complex and highly specialised.

### **Artificial Intelligence**

The practical aspects of creating the system described require the development of nonmonotonic reasoning systems that mimic common sense reasoning, that attempt to make decisions and to reach conclusions in an ambiguous world (Boutsinas & Vrahatis 2001). Nonmonotonic reasoners play an important role in this type of development, however, there are two general problems encountered in such knowledge based systems namely the strong dependency on the correctness of the underpinning domain knowledge and the lack of domain independent and effective learning algorithms. Combining Nonmonotonic reasoners with Artificial Neural Networks produces a neural-symbolic hybrid system that is capable of overcoming the difficulties that are encountered by each system in its separate state. (Boutsinas & Vrahatis 2001)

The Artificial Nonmonotonic Neural Network (ANNN) possesses a domain knowledge that is used for the initialisation of an artificial neural network. The latter is an example based learning mechanism for the refinement of the initial knowledge through processing a set of classified examples. After the refinement, the acquired knowledge is extracted substituting an initial domain knowledge. At this stage a new cycle of knowledge – refinement – extraction can start, whenever a new set of examples needs to be considered. Domain knowledge is represented by a nonmonotonic multiple inheritance scheme allowing exceptions. More specifically, Nonmonotonic Inheritance Networks that are based on semantics networks are used. (Boutsinas & Vrahatis 2001)

In the practical care environment learning conforms to culture, and learning styles vary between learning systems. However, where experiential learning enables people to make predictions, development of the learning environment into which the learning system can be embedded requires the following considerations:

- Knowledge acquisition – the development of skills, insights and relationships;
- Knowledge sharing – the dissemination of what has been learned;
- Knowledge utilisation – the integration of learning so it is broadly available and can be generalised to new situations

(Nevis, DiBella, Gould, 2002)

The volume and type of information that can be input to the ANNN system are practically limitless, as are the practice procedures that can be augmented by intelligent applications contained within them. Therefore, the ANNN system can be trained to provide information drawn from small or large data sets, to perform data processing that

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recognises trends and makes predictions. The output enables proactive (cost-effective) intervention through identifying specific care practices for individuals or for organisations, or for training policies which can have predictable outcomes. The resulting evidence driven practice, further contributes to the development of the information base to improve the quality (validity and reliability) of the data and allied analyses.

Once the ANNN system has been trained to learn, the ongoing supplement of data facilitates its evolutionary growth. In this way, the system allows for interrogations based on data and text mining for information on trends, patterns, and clusters in the practice, management and outcomes of care. The data queries can be topic specific, such as processes for dealing with challenging behaviour; 'best practice scenarios' for supporting community access; outcomes data for developing sexuality and relationship programmes, and so on. The searches can also provide non-parametric inferencing, where the generalised statistical and text patterns discovered through mining can be tracked back through the case-studies to find real-world explanations. In addition, the creation of computation algorithms to speed up query responses, along with the use of intelligent programs to create genuine inferences and predictions, when combined with qualitative analysis, provide the opportunity to improve the efficiency and quality of short and long-term support processes for all vulnerable individuals.

Mining data across a range of care providers yields statistical data which may, for example, relate to pharmacological interventions (akin to a clinical study); or inform specific practices which relate to challenging behaviour. Identifying the cluster to which any given individual entering the system of support belongs, may locate an appropriate package of support for that individual.

As the information base evolves, participants are placed in the unique position of being informed on many dimensions. For example, the outcomes of process mining life-style planning and analyses of programmes become more finely focused on the needs of the service user (van der Aalst 2003). This results in the design and delivery of cost-effective support packages which can support clear Quality Assurance processes of:

- maximised efficiency in care processes leading to a reduction in costs
- Interactive access to information, facilitating self-assessed identification of support requirements
- reliable evidential bases for the development of new care provisions
- compliance with current legislation
- secure access to and storage of information
- continuous updating and monitoring of additional information

An example of a practice procedure that has an intelligent algorithm embedded within it is the enhanced 'individualised programme plan' or iPlan. This solution is able to be adopted independently, but also links with other organisational practice procedures to offer a complete range of applications.

### **iPlan Example**

Most service providers will be familiar with the development of Individualised Programme Plans (IPP) for a service user's immediate future life choices. This is a

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process where a service user is regularly supported by key individuals to review the previous plan, and to decide whether to amend the goals within it, or to make a new plan for his or her immediate future. Currently, this is an exercise involving parents, social workers, advocates, members of staff and the person, who meet to discuss the next short phase e.g. six months, in the person's life, and the outcomes are recorded on paper.

Although this is intended to be an equal opportunities experience for everyone to share their views and to collaborate on the way forward, in reality it rarely works in this way. Most meetings involve people whose levels of ability to contribute are unequal for a variety of reasons. For instance some individuals may not be as well informed as others, or as articulate, or as experienced perhaps. The relevant information that would redress this imbalance may not be readily available to those who need it, or they may not know where to look for it.

The new iPlan application resolves these issues instantly. The basic framework is a measuring process of selected content, which is then compared to pre-determined criteria. For example, the criteria may contain the components for representing support requirements for a person with an Autistic Spectrum Disorder. When the input data from all participants is measured against these criteria a profile of support requirements for that person emerges.

What is being measured is the perception of an individual's support requirements as presented by the individual, plus all significant people in making life decisions for that person. The resulting iPlan report comes in two forms, one for use as an agenda for the subsequent meeting, and a second for use in clinical analysis. The reports provide evidence for understanding the difference in perceptions, with a view to consolidating these differences and reaching an acceptable compromise with the individual for future life activities, in this example, a period of 6 months. The whole process is led by the person and is, therefore, empowering.

The additional advantages of the iPlan are the indicators for practice enhancement contained within the individual responses:

- The person's self perception is clearly depicted
- Achievement and progress are emphasised and efforts are measurable
- Comparisons of responses may show discrepancies which may indicate a need for sharing information more effectively (for instance with social workers or those external to the service provider)
- Differences of opinions may emerge (for instance between parental views and staff views), and these provide an opportunity for opening dialogues to address any issues of conflict
- there may be a marked deviation of perception within staff responses which may indicate a training opportunity
- there may be an indication of success or failure of intervention processes which would benefit the Intervention Planning Team meetings
- the whole process is continuous, recorded, stored and available as evidence, which is vital for long term support planning
- the data is stored securely in an electronic digital vault accessible only to those with the correct permissions

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iPlan is accessed as an online managed service which alleviates any arduous administration for the organisation or individual. The service is straightforward, quick and easy, and operates similarly to an online 360 staff appraisal (www.feedback360.net) ie named participants would be invited via email to respond to the questionnaires, within a set time frame. The auto-generated report would then be distributed to participants prior to the iPlan meeting, and in sufficient time to provide more information where necessary. The meeting takes place with the Chairperson using the report as the basis for the meeting agenda and the outcomes are recorded in the iPlan online form. With each successive iPlan a synopsis of the previous iPlan report and outcomes is included. However, a comprehensive report containing full evidence, which is extremely useful to practitioners, is also available online to those with the appropriate levels of security and permission.

The circulation of information prior to the meeting enables and empowers the individual by giving her or him a voice and by providing equal opportunities to participate for each person involved. The continuous layering of information with each subsequent iPlan means that continuity is never lost and long-term progress, patterns and trends can be easily identified. iPlan is but one example from a range of procedures that can be supported online and that have intelligent algorithms embedded within them.

### **Intelligent Solutions in Practice**

Each application facilitates the recording and collection of data online, using mediums for data input and secure internet access that are acceptable to staff and suitable to the environment. The adoption of the range of intelligent solutions to augment practice creates an organisation-specific platform for sophisticated knowledge and process management to support the person-centred development of support for their service-users within individualised settings (van der Aalst 2003). This dynamic process creates a loop that links theory with practice and practice with evidence, and enabling organisations and individuals to have access to information that is relevant to their specific goals and that is based on theory driven practice and evidence. This access informs multi-care processes at various levels and stages of service development, and leads to models of good practice.

Using iPlan as an example, we can illustrate the growth of support procedures that are collaborative and empowering with a complete audit trail of evidence that forms a secure foundation for the personal and interpersonal development of each individual. Each person is enabled to structure their own life enhancement to lead towards the fulfilment of his or her potential. The comprehensive audit trail of evidence supports the recognition of the quality of life criteria, which are likely to be idiosyncratic, for each individual, and on this basis predictions can be made for future life-style management and enhancement.

The value of this process can be appreciated by:

- Service providers – particularly where they are operating trial and error interventions and especially where compliance with legal standards is a requirement

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- Parents – especially where they are remote and feel excluded or lacking in information/evidence or have difficulty in getting their views heard
- Individuals – where they have a right to choice, autonomy and inclusion, and need to have some control over their future but lack the skills for full participation
- External professionals – particularly where they need comprehensive information and when they are involved in significant decision-making

The effect of combining procedures creates the rhizomatic network of dynamic growth of shared evidence, knowledge, and emergence of new reliable information. This has far reaching effects for any organisations/individuals involved in evaluative supportive procedures, regardless of the industry or field.

Intelligent solutions that are used for the purpose of research provide invaluable sources of evidence for intervention procedures such as pharmaceuticals, behaviour management strategies, and could also yield information on the patterns and trends in individuals with anti-social behaviours and could have a part to play in penal reform. The value is maximised when all the solutions are implemented together, as they are interdependent, and together they act like cog wheels to make the gears shift and create movement. That is not to say that the independent operation of a single intelligent solution will not enhance service provision. In fact, because the transition from the culture of paper-based systems is a gradual process, adopting these solutions one by one will enable an organisation to transform its level of service excellence at an acceptable and achievable pace.

It remains essential for the communication channels to be open between all the agencies and individuals involved in service provision (this involves parents and professionals), therefore, solutions must be sufficiently flexible to allow exchanges between the variable systems that are in place. Progress occurs at varying rates, and during the transition stages service providers are nonetheless required to be transparent and accountable at all times in their practice, whilst remaining fully compliant with the legislation. Accountability is hugely significant for bodies such as the Care Standards Commission Inspectorate UK, and the Commission for Health Audit and Inspection 2004. These organisations are obliged to assess the levels to which service provisions are complying with the legislation and with regulations pertaining to care. The inspection processes are evaluative but subjective, although they are intended as objective measures of compliance with the legislative standards of provision. The introduction of secure intelligent solutions to the inspectorate would enhance their efficiency, foster cross-cultural applications, whilst enormously reducing costs and regional variations in inspections.

The crucial difference in these intelligent solutions compared to other highly sophisticated data management and evidence based procedures, is the *versatility*, ie the facility to manage diverse content within the same framework. The technical structure for data input is standardised, and is, therefore, adaptable to any culture, but the data content is focus specific and the procedure involving the intelligent algorithm is outcomes led so that support is always focus-centred – whether the focus is the person, or the quality of services, legislative compliance, etc.

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### **The Person at the Centre**

The application of IT solutions in the health industry is controversial particularly given the massive Government spend in recent years with seemingly poor returns. There are real risks that automated services can either exclude the practitioner, and/or can reduce the individualised aspects of support in favour of generalised solutions which may maximise the efficiency of the administration, but which may overlook the individual. Where person-centred support is the central tenet of an organisation's philosophy and ethos, and where Rights and Quality of Life are essential considerations, the introduction of electronic solutions to services may, therefore, be met with healthy scepticism. Consequently, the introduction of intelligent solutions that play subordinate roles to the practitioner, but which significantly augment their practice, is a major step forward in the field of person-centred evidence-based practice.

The increased uptake of the intelligent solution supported practice would engender significant shared benefits for service providers across the globe, such as:

- Maximising the effectiveness with which support is delivered
- Sharing knowledge and making it accessible to all
- Facilitating the globalisation of person centred support
- Evidence based practice
- Multi-cultural – Multi Lingual
- Multi industry

Access to this extensive resource of robust knowledge will provide a considerable variety of advantages for practitioners. For instance, the efficiency of practice procedures will be increased, allowing staff to spend a greater proportion of their time on the human elements of their role in delivering support. The amount of support required will reduce with the increase of appropriate treatments and interventions. Training and knowledge acquisition will be enhanced through the facility to exchange experience with other practitioners. Strategic care providers (LHA's and LEA's) will be better able to collaborate with service providers to define and match 'needs' in ways which will avoid catastrophic entry into care, which has been a long standing problem in the care industry. Finally the joint agencies, Local Health Authorities, Local Education Authorities, and Social Services, will be able to access the day-to-day information they need, together with strategic data related to cost-effectiveness and programme outcomes, to ensure that services are evidence based to produce truly person centred support.

Service design and delivery are symbiotic with the underpinning philosophy and ethos of service provision. The introduction of intelligent solutions to support practice, will, therefore, have significant impact in a range of areas for the person who has complex needs, both in the short and long term, particularly where Rights (see Appendix 1) and ethics play significant roles as in:

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- The social construct of complex needs eg 'Autistic Spectrum Disorders'
- Diagnostic procedures
- Assessment and evaluative procedures
- Care planning
- Challenging Behaviour
- Treatment/therapeutic regimes (Interventions)
- Medico-Biological responses in intervention practice
- Parental support and inclusion
- Staffing issues, directions and quality issues in developing professional development and training
- Economy

In addition, enhanced efficiency in the identification of service user needs will support the clearer understanding of the costs of designing effective support packages and allow for improved negotiation of more appropriate fee structures for given service users, to the benefit of the individual, their family and both purchasers and providers.

Broadly speaking, the areas taken into account in the development of support provisions are:

- The range of considerations involved in producing good quality of life (see Appendix 3)
- variations in human characteristics, personalities, and physiological traits
- socially constructed and environmental influences and/or constraints
- Rights (see Appendix 2) and entitlements within social structures
- Processes in decision making

*(all of the above are fluid and change with time)*

These processes are dynamic, continuously evolving with the personal development of the individual, and subject to existing socio-economic constraints, as well as being influenced by the underpinning philosophy of the service provider.

The specific intelligent management of data can provide the basis of a significant ethical opportunity to provide a coherent process of organisation mapping, identifying directions for change and providing the training and management support to achieve it. In addition, the cohesive process of providing customised support packages within organisational frameworks presents the opportunity to introduce bench marking overviews. This differs from existing accreditation frameworks which do not offer dynamic opportunities for collaborative working across partnerships.

### **Wider Implications**

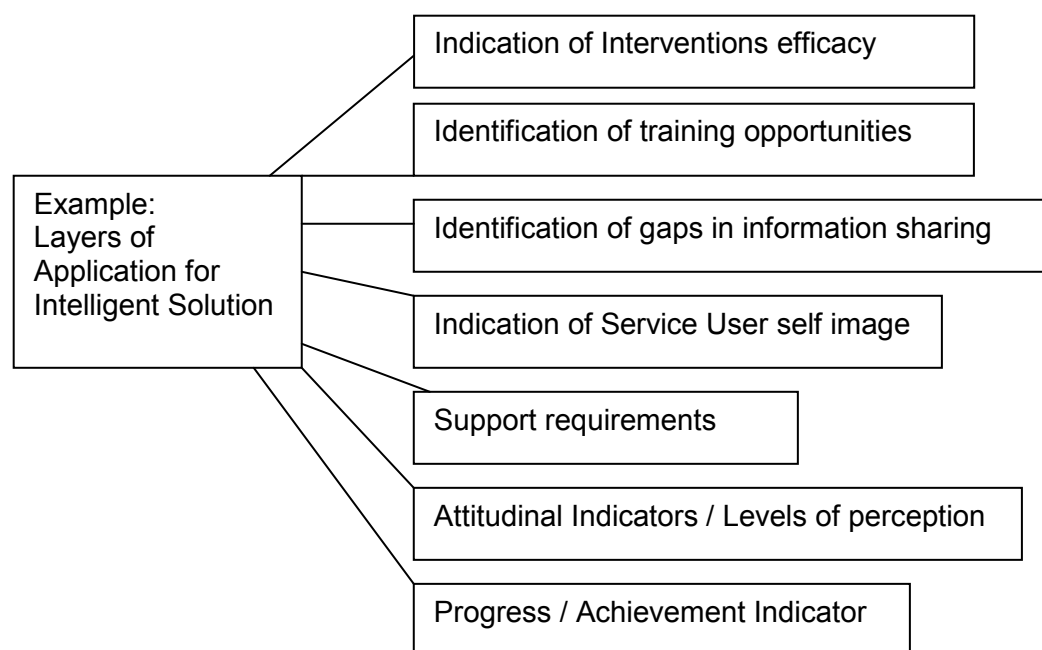
The output from the collective intelligent solutions will provide an extensive potential resource that will inform the Health and Social Care industry as a whole, with specific significance for the roles within it:

## INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT

- for the service user, the interrelationship of these two constituencies offer opportunities to provide patterns of care which can make real change in the area of quality of life
- for parents - real understanding of what is available and what is required to support their child or children
- for direct care service personnel - a range of evidence based strategies which offer real opportunities for change and growth in the individual and increased understanding
- for managers of care - the improved understanding of 'best practice' within cost-effective models which conform to Codes of Practice and ethical/legal systems

Because each intelligent solution produces multiple layers of knowledge, these can be applied differently across wide ranging support procedures (see Figure 2) such as the further development of training manuals and programmes. The infinite range of data that is able to be processed means that 'personal narrative', 'life-history' and biographical (text) data can all be mined to obtain evaluative indices, such as quality of life, which underpin ethical practice. This multi-disciplinary facility can be applied to any evaluative procedure and is of benefit, not only to the Health and Social Care sector, but to many other industries as well.

**Figure 2: iPlan Applications**



The essential aspects of these intelligent products and services, for service providers and the recipients of services, are: their ease of use and low cost of implementation; the varying layers of application: the value which can be added to information through analysis: the facility to gather and share this information securely. The data that are used are gained through real experience, and the different levels of application offer practice support in the form of validated information to a wide range of providers:

- Clinicians (psychologists, psychiatrists)
- Academics
- Teachers

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- Related Services e.g. Legal Advisors, Advocates, Care Home Advisors, Therapists, Social Workers
- Care-related organisations e.g. pharmaceutical companies, prosthetics designers and manufacturers
- Training/Care related designers e.g. Virtual Reality software/hardware

As a research resource, these solutions could provide access to detail, within an ethical framework that has far reaching effects. For instance, when used individually or collectively, the nature of epidemiological studies could be revolutionised. Introducing secure methods of recording and accessing such critical data would create the opportunity for conducting studies on large populations but with detailed depersonalised information on each member of that population. The output would be in the form of validated evidence based information that could reliably inform the public on topics such as the costs and benefits of pharmaceutical treatments, and the success and failure rates of therapies, as well as many other life influencing factors and embracing all cultures and languages. A further 'value-added' facet of evidence based practice will be the ability to perform data, text, knowledge and process mining (van der Aalst 2003) to provide the hitherto elusive 'Quality of Life' indices for each individual, ensuring that support strategies move and develop appropriately with ever changing needs.

It is hoped that the far-reaching consequences of globalised implementation of these intelligent solutions would create seamless transitions between services, whilst providing continuity through appropriate dynamic support. Practitioners will be enabled to recognise quickly when systems are not matching the needs of the individual, and to rectify these situations accordingly. The improved speed with which emergency behavioural assessments could take place would facilitate the immediate appropriate support responses and, ultimately, the frequency of challenging behaviours that require extreme interventions such as containment and restraint will be significantly reduced.

To illustrate some of the areas where the intelligent solutions could influence service provision please see Appendix 1 'Multiple Applications of iPlan', which contains a series of vignettes based on real life experiences of one adolescent with Asperger Syndrome. An attempt has been made to illustrate the potential solutions on offer through the versatility and flexibility of the iPlan structure, which enables it to be customised to any environment and any activity.

# INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT

## References:

- Bayliss, P., Heather, D., Wood., J., (2001). '*Biomed Project for Autism Report*'. University of Exeter / DCACT, Sterling Court, Truro Hill, Penryn, Cornwall TR10 8DB.
- Boutsinas, B., & Vrahatis, M., N., (2001). '*Artificial Nonmonotonic Neural Networks*', Artificial Intelligence, [www.elsevier.com/locate/artint](http://www.elsevier.com/locate/artint)
- Daunt, P., (1991), '*Meeting Disability*'. London: Cassell.
- Deleuze, G., & Guattari, F., (1987). '*A Thousand Plateaus: Capitalism and Schizophrenia*', (translation: Massumi, B.), Minneapolis: University of Minnesota Press,.
- Douglas, H., R., Greenhalgh, P., (1997). '*A training needs analysis of primary health care teams for evidence-based health care in North Thames region.*' Unit for Evidence-Based Practice and Policy, Department of Primary Care and Population Sciences UCLMS/RFHSM, Whittington Campus, London N19 5NF.
- Knapp, M., & Jarbrink, K., (2000) '*Cost of Autism in the UK*'. London: Mental Health Foundation.
- Koegel, L., K., Keogel, R., L., Dunlap, G., (1996). '*Positive Behavioral Support*'. Paul H Brookes Publishing Company Inc., P. O. Box 10624, Baltimore, Maryland, 21285-0642
- Nevis, E., C., DiBella, A., J., Gould, J., M., (2002) '*Understanding Organisations as Learning Systems*', [file:///F:/learning\\_sys.html](file:///F:/learning_sys.html)
- United Nations (1988). '*Universal Declaration of Human Rights*'. General Assembly. <http://www.un.org/Overview/rights.html>
- van der Aalst, W., M., P., 2003. '*Business Alignment: Using Process Mining as a Tool for Delta Analysis*'. Department of Technology Management, Eindhoven University of Technology, PO Box 513, NL-5600, Eindhoven, The Netherlands.
- [www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities](http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/LearningDisabilities)

Special thanks to:

New Futures Group

[www.newfuturesgroup.com](http://www.newfuturesgroup.com)  
[www.feedback360.net](http://www.feedback360.net)

Spectrum

[www.spectrum.com](http://www.spectrum.com)

iSentry Health and Social Care

[www.isentry.com](http://www.isentry.com)

Time Out For Families internet support group for children with disabilities

[www.timeoutforfamilies@yahoogroups.com](http://www.timeoutforfamilies@yahoogroups.com)

# INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT

## APPENDIX 1 – Multiple Applications of iPlan

The following information is fictitious but based on a real case a young man with Asperger Syndrome. The names are purely fictitious and do not relate to anyone.

### General Information

David is 17 years of age and lives with his parents. David has a history of behavioural difficulties which appear to be increasing in severity as he gets older. His behaviours have led to his suspension from school, several arrests, and imprisonment.

The options for specialised support are minimal and existing service providers are becoming less able to provide for his needs. There appears to be a lack of understanding across both service providers and the judiciary as to how Asperger Syndrome causes the person to behave, and therefore, what the appropriate support strategies should look like.

The nature of the challenging behaviour and the absence of appropriate support mechanisms available from the various agencies, (health, education, social services and the judiciary) are imposing considerable strain on family life. In turn this is affecting the health and well-being of siblings, parents and other family members.

### Catalogue of events:

#### May 2004

*'David got suspended (from school) this week for the 3rd time in as many weeks. Last week it was an arrest and suspension. He is struggling with issues of fairness, and is being extremely disruptive when things are not going well, plus he isn't responding to staff intervention; principal describes it as completely insubordinate behaviour. To top it off, he was mouthy to a police officer, not a wise move.'* (Parent)

The **iPlan education plan** offers the opportunity for families, educational staff, external agencies and advocates to become involved in negotiating an appropriate educational support regime both in the short and long-term. It also ensures that all participants are made fully aware of essential person-specific information, that all procedures are recording thus equally ensuring continuity, even when staff members change or new individuals become involved.

#### June 2004

*'We have been to Court twice recently to answer to 2 separate charges in different counties with more coming up. The Superior Court case has offered David an application for the Youthful Offender Program (I need to learn more about what this is comprised of). The Juvenile Court has assigned him a Probation Officer and the case is being held open. Meanwhile JC has also ordered additional evaluations.'* (Parent)

The **iPlan online** facility provides an opportunity for information to be shared remotely with all relevant parties ie the court representative, Probation Officer, Parents, David, and any other individuals who contribute to the decision-making process. This is an inclusive, empowering process that provides equal opportunities for people to participate.

#### July 2004

*'Yesterday's incident pales in comparison to the whole trend that is establishing itself a growing criminal record, probation in adult and juvenile court, cases in progress and warrants yet to be issued. It was the decision of the court to remand him to a correctional facility(jail), which houses an adult and youth(16+) population.'* (Parent)

The decision to place David in a correctional facility indicates both a lack of understanding of the nature of Asperger Syndrome and/or the lack of appropriate support facilities. The **iPlan pre-placement assessment** process provides indicators for a person's specific support requirements, whilst giving insight into symptom manifestation, appropriate support strategies and individualised programme planning.

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### August 2004

*'If I could live out my dream I would create a parent liaison position within our local police department and in the ER of the hospital in a nearby town. There are times when a parent can be a huge asset to a family in crisis.'* (Parent)

The **iPlan liaison** facility offers an opportunity for parents, service providers and the joint agencies eg Health, Education and the Police, to exchange information securely. This would provide access to previously negotiated programmes that also illustrate the individual's specific difficulties, whilst providing an intelligent method of negotiating an appropriate immediate support response.

### September 2004

*'It was \*\*\* hard to see my son 16 years old and mentally ill stand before me in leg shackles and handcuffs. The balance of treatment vs. justice is truly hard to figure out.'* (Parent)

The lack of understanding of the behaviour that challenges and also contravenes the law, results in the misconception that people with ASDs, who are high functioning, understand the consequences of their actions and will, therefore, respond to punishment and/or rehabilitation. The introduction of the **iPlan intervention plan** would inform the law enforcement and support agencies and, thereby, facilitate the design of an appropriate, alternative programme for behaviour management through empowerment.

### October 2004

*'The other issue is that the issue of David's future placement seems to be revolving around which agency is going to take responsibility for it.'*

The **iPlan care plan** programme identifies a person's strengths and weaknesses and in which specific areas of functioning he requires the most support. This is an inclusive process that involves the joint agencies, enabling them to work with the family, to clarify areas of responsibility, to negotiate the best support programme, and to allocate the essential resources. This has significance for stake-holders where resources and budgets are limited and under pressure.

### November 2004

*'He is in a mental health unit temporarily, as they assess his status. He will be moved to a youthful offenders unit, within the general population or possibly be transferred to a more specialized correctional facility that has more the ability to address the treatment issues.'* (Parent)

*'David has had a couple of 1 week stints in a segregated cell (solitary). He is usually in a mental health unit cell, with a cell mate. He does not get his phone privileges back until mid August, but we can exchange letters in the meantime. We have also applied to be put on his visitors list - no word yet on that.'* (Parent)

The **iPlan behaviour analysis** provides an intensive detailed study of specific areas of difficulty. This would provide a sound basis for an intervention plan for David, in which he could engage fully and that would empower him.

## INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT

### December 2005

*'The first 2 weeks marked a honeymoon period for David at the hospital, an amount of time not atypical for this type of situation. He did pretty well, and didn't need much staff intervention, responded to re-direction when given.'*

*Monday night was the end of the honeymoon. He reacted poorly to teasing by other patients - a sign had been placed on his door that he had early bedtime. He threw a piece of fruit across the room and required a "soft escort" to the seclusion room.*

*That's where the meltdown really started. He was kicking the door, tried to leave the room and even ruined his own sneakers, swearing - the works.*

*This necessitated a stay of over an hour in seclusion and a PRN med, in this case thiorazine. I think this may be one of the topics at our family session this week, which just happens to be the first one.' (Parent)*

The **iPlan stability record** highlights the influences affecting the person and also illustrates any trends or patterns of behaviours. The intelligence within the system enables predictions to be made for the most effective intervention solutions which would be of great benefit to David.

### February 2005

*'I am uncomfortable with professionals using a word like normal (in terms of a prognosis) when Asperger Syndrome is a neurobiological disorder it is not a disease.....' (Parent)*

*'The clinician that saw David for intake will not be seeing him again. The team at her agency met and decided that he is not a good candidate for outpatient therapy. In this area therapists work in conjunction with the med doc; absence of therapy means no services from the psychiatrist.' (Parent)*

The **iPlan staff performance evaluation** provides insight into further opportunities for training and specific areas of focus for staff members.

### March 2005

*'Yesterday was pretty rough. I got a call from David's school that he was ignoring requests to stop smoking. The behaviours escalated to the point where he ran into the adjacent road thru traffic and then laid down in a travel lane. He was also talking about how tough it is to live and be him.'*

*When he realized that emergency personnel were coming to get him out of harm's way, he bolted into the woods. The police had to fish him out and he was sent to the ER.*

*This resulted in an inpatient hospitalization. Several places were called and had no beds. One of them had a bed, but refused David as a patient [ history of fire setting ]. The last call was the best one and he has gone back to the facility that he was discharged from 4 weeks ago.*

*David is at the end of his first week of this hospitalization. He seems angry and somewhat withdrawn, saying he doesn't want much to do with us and will not be coming home. His view is that **we** did things that made it impossible for him to live at home and led to the hospitalization.' (Parent)*

The **iPlan risk assessment** process identifies the areas of risk and calculates the level of potential danger. In addition, it indicates the levels of support required to engage in specific activities. This process is invaluable in creating an empowering future programme with the individual. The continuity and central involvement of the person, in this case David, create a sense of autonomy, of having some control over his future.

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**March 2005**

*'He did call home a couple of times. His topic of conversation was when was he going to get his "stuff" brought to the hospital. Right now, he has his clothes, but we are holding back on most of his other items, such as electronics and money. He wants to put the radios and scanners etc in storage where he is; we think they will be safer at home. For him this is a source of contention.'* (Parent)

*'This time around, David is dealing with suicidal thoughts, which is a new thing. In addition to the suicidal acting out, he has been cutting.'* (Parent)

The disempowerment that David is experiencing is adversely affecting his mental health. Treating the symptoms in this case is not going to resolve the issues that arise from long term support, which, by default, may be intrusive and dis-abling. In this situation the **iPlan individualised programme plan** would elucidate the areas in which support strategies are required. In addition, iPlan would identify any anomalies or imbalances that need to be addressed, and would consolidate the different views of those involved so that they become a team that can move forward together, with David in the lead.

**March 2005**

*'David has been verbally resistant to meds in the past, although he took them just the same. I hope that depakote trial turns out well. I think he will become more resistant, if he has to get on the proverbial med merry go round.*

*A med review might be helpful, although after all of this time, meds have not led to any sort of prolonged stabilization. The doctor asked for permission to try an antidepressant, Prozac. The plan is to start with a super baby dose and titrate from there; with a careful eye on side effects.'* (Parent)

*'Concerta would be a great choice for me, I looked into it. Unfortunately, it is cost-prohibitive, which is why I am doing all this research on a less expensive alternative. At present David is on:*

- Depakote 1000 mg
- Seroquel 300 mg
- Buspar 10 mg x 3.'

The **iPlan medication** process creates a profile of person's medication history, and highlights the benefits and contra-indications for existing and proposed drug therapy.

**March 2005**

*'Another loose end to be tied up was getting David's meds to school. We have been down to one car for the past couple of years, so I am completely unable to drive them in and my husband works 50+ miles from the school. I made a couple of calls and could feel my frustration increasing. His DCF social worker authoritatively stated that my husband, who has the car is obligated to take time from work to get the meds to school, no matter what repercussions may ensue.....argh!\*&^\$#@\*+|*

*As you can see, I have a sense of frustration with case workers or other providers who cannot "meet their clients where they are, not where they'd like them to be.'* (Parent)

The **iPlan family support** process provides the opportunity for parents and professionals to review practical solutions to the issues arising from creating a sustainable support network around an individual who has complex needs.

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### **March 2005**

*'For my own peace of mind I have contacted a state level "watchdog" agency - The Office of the Child Advocate. They will be looking into the matter from the perspective of David's civil rights and best interests. I called them because I have some concerns about the timeliness and appropriateness of the execution of all the various responsibilities entrusted to others in this situation.'* (Parent)

*'When you are able to climb out of your own back yard to advocate-do it! There is much room for systems reform, in children's mental health, the justice system, and in insurance issues. Regrettably, the first two systems often come together due to a lack of continuity in children and families really need.'* (Parent)

The **iPlan advocacy** programme provides support for individuals, their families, and the joint agencies to grasp a full understanding of a person's needs and desires. The process facilitates the negotiation of future planning with the person, so that best practice can be implemented leading to enhanced quality of life for all concerned.

Please note:

1. The above solutions realise their maximum effect when deployed collectively.
2. Additional intelligent solutions are available to augment the creation of new services, policy writing, and various evaluative procedures.
3. At no time are these solutions designed to substitute for personnel, nor are they intended to be used as diagnostic or prescriptive measures independently of clinicians.

# INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT

## APPENDIX 2 - Charter of Rights for Persons with Autism

The United Nations Declaration on the Rights of Mentally Retarded Persons (1971) and the Rights of Handicapped Persons (1975) and other relevant declarations on Human Rights should be considered and in particular, for people with Autism the following should be included:

1. The Right of people with Autism to live independent and full lives to the limit of their potential.
2. The Right of people with Autism to have access to an unbiased and accurate clinical diagnosis and assessment? (DSM-IV): The assessment and diagnosis will be carried out by competent agencies familiar with a wide range of psychiatric disorders, including Autism. The diagnosis should be carried out with no vested interest in the outcome of the diagnostic procedures; the results should be communicated to the person afflicted (where appropriate and/or their relatives or those responsible for their care).
3. The Right of people with Autism to have access to appropriate education, which includes the Right to:
  - education for specifically autistic people.
  - individualised assessment by experienced educationalists and related to outside agencies not directly related to the provision of care.
  - individualised education and IEPs.
  - education in the least restrictive environment.
  - the benefits of tuition for pre-school children.
  - parental and familial involvement in the education programme.
  - constant monitoring against set criteria: therapies should be tried and tested, and, if necessary abandoned: the range of possibilities should not be limited by dogmatic principles.
  - no financial burden on families involved.
4. The Right of people with Autism (and their representatives) to be involved in decisions affecting their future; the wishes of the individual must, as far as possible, ascertained and respected.
5. The Right of people with Autism to have access to suitable housing.
6. The Right of people with Autism to have access to equipment, assistance and support services necessary to live a fully productive life with dignity and independence.
7. The Right of people with Autism to have access to an income or wage to provide adequate food, clothing, accommodation and other necessities of life.
8. The Right of people with Autism to participate in the development and management of services provided for their well-being.
9. The Right of people with Autism to have access to appropriate counselling and care for their physical, mental and spiritual health, including the provision of appropriate treatment and medication administered in the best interests of the patient with all protective measures taken.
10. The Right of people with Autism to have access to meaningful employment and vocational training without discrimination or stereotype; training and employment should have regard to the ability and choice of the individual.
11. The Right of people with Autism to have access to transport and freedom of movement.
12. The Right of people with Autism to participate in and benefit from culture, recreation and sport.

## INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT

13. The Right of people with Autism to have equal access to and use of all facilities. services and activities in the community.
14. The Right of people with Autism to have sexual and other relationships, including marriage, without exploitation or coercion.
15. The Right of people with Autism (and their representatives) to have access to legal representation and to the full protection of their rights.
16. The Right of people with Autism to be free from fear or threat of unwarranted incarceration in psychiatric hospitals or other restrictive institutions.
17. The Right of people with Autism to be free from abusive physical treatment or neglect.
18. The Right of people with Autism to be free from pharmacological abuse or misuse.
19. The Right of people with Autism to have access to all information contained in their personal, medical, psychological, psychiatric and educational records.

Presented at the Fourth Autism-Europe Congress, Den Haag, 10 May 1992.

## INTELLIGENT SOLUTIONS, EVIDENCE BASED PRACTICE AND LONG TERM SUPPORT

### APPENDIX 3 – Quality of Life

“[The superiority of the quality of life for all people with disabilities] over independence in the hierarchy of goals is confirmed by the fact that individuals may vary in the degree to which they want to be independent but not in the desire for a good quality of life.

The concepts of independence is a self-defined one which varies from person to person.

Of such a good quality of life we were able to identify these components:

- autonomy: the freedom to choose a preferred way of life
- independence: the opportunity to make one’s own practical decisions; encouragement not to be over dependent in everyday matters
- integration: acceptance by society as a fellow citizen and member of the community, with full political as well as social rights; freedom from marginalisation
- respect: recognition of the value of one’s identity and role, and of one’s contribution to the lives of others
- ownership: the possibility to keep one’s own personal possessions and retain control over one’s own finances
- social involvement and communication: access to a range of useful and interesting occupations, of educational experiences and cultural, leisure and self-help activities; encouragement and support in undertaking these; availability of an accessible environment, including transport
- privacy
- tranquillity: freedom from noise and disruption; continuity of place and environment

Daunt, 1992, page 175