

The Practical Application of a Meta-Analysis of Deinstitutionalization: Adaptive Behaviour  
Outcomes and the Piloting of a Transitional Questionnaire for Adults with Intellectual  
Disabilities

Jeffery P. Hamelin, B.A. (Honours)

Centre for Applied Disability Studies

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Faculty of Social Sciences, Brock<sup>1</sup> University  
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Abstract

This investigation examined the effects of deinstitutionalization on the adaptive behaviour and adjustment of adults with intellectual disabilities (ID). In study 1, a meta-analysis was conducted with 23 studies on deinstitutionalization adaptive behaviour outcomes. Deinstitutionalization was associated with modest improvements in adaptive behaviour however outcomes varied across adaptive behaviour domains and other substantive variables. Clinical and service implications of these results were explicated. Noting the trends from the meta-analysis, study 2 used this information in refining and piloting an Agency Transition Survey used to evaluate community transitions for persons with ID. Information derived from the survey was found to be valuable and adequate for the effective evaluation of transitional success. Potential applications of the survey and meta-analysis results were illustrated.

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The advancement of deinstitutionalization (the movement of persons with intellectual disabilities into smaller residential settings) has proven to be complex in its application and scope. It can represent a significant transitional experience for those undertaking it. The influence of this process on the lives of persons with intellectual disabilities (ID) is determined by a number of variables including the types and level of supports offered as well as the setting to which someone moves. The significance of this impact is expressed along a number of dimensions including the degree of community integration or choice, family contact, quality of life and challenging or adaptive behaviours. All of these dimensions can be seen to be dependent on the level of adaptive or daily living skills that one possesses. The potential for long-term effects based on this impact makes it prudent to closely examine the factors that underlie the process and how these translate to application in the community. For these purposes, a targeted meta-analysis of deinstitutionalization adaptive behaviour outcomes was conducted in order to reveal which factors and conditions predicted habilitation following community placement. Common deficits were also examined. These results were further applied in the refinement and piloting of a transitional survey for persons with ID. In this way, the transitional process could be better evaluated and the appropriate individualized supports and arrangements identified.

Deinstitutionalization has progressively become the standard of care in most developed countries. The deinstitutionalization process was slow to develop, initially arising in the late sixties and early seventies and continuing today. The process itself was predicated or fostered by

a number of associated social movements, shifts in political philosophy, and legal actions (Landesman & Butterfield, 1987). The advocacy of parent organizations and growing human rights issues led policy makers to place higher priority on funding and community living for persons with intellectual disability (Neufeldt, 2001). Providing a philosophical underpinning for this movement was the principle of normalization originating in Scandinavia and later championed by Wolf Wolfensberger in the United States, “The normalization principle means making available to all people with disabilities patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society” (Nirje, 1985, p. 65). The normalization principle, though not equal to deinstitutionalization, certainly alludes to such a process. Segregating persons with intellectual disabilities in large institutional environments obviously reduces the potential for a normalized lifestyle (Whitman, 1995). The specific goals of deinstitutionalization, tied to the promotion of greater inclusivity, choice and quality of life for persons with ID, simply represent further branches on the tree of normalization (Johnson & Traustadottir, 2006). Meaningful community integration is now the hallmark of care for individuals with ID.

The application and histories of deinstitutionalization differ across countries however much of the process relates back to the normalization principle. Large institutions were often downsized with residents moving to smaller hospitals, units, or clusters in the community. More recently the trend has continued to develop with the provision of services and support across community group homes (2-6 residents) or semi-independent living arrangements (Young & Ashman, 2004a). These group home settings are expected to foster the goals of normalization and provide more habilitative elements than previous institutional environments.

Although normalization and its progeny, deinstitutionalization are now accepted practices their instigation and continuing implementation is not without controversy (Landesman & Butterfield, 1987). There is little doubt that community placement is more compatible with human rights and certain quality of life issues but it is not without risk. Opponents of the process have raised issues regarding the quality of care provided in one setting versus another such as environmental safeguards, well-trained staff and access to clinicians and healthcare (Landesman & Butterfield, 1987). In particular some have questioned the extent to which current service provision is fulfilling the original purposes of deinstitutionalization. In Canada it has been argued that,

The lives of individuals with developmental disabilities in Canada are changing...It is evident, however, that the gap between the community living ideology and social policy persists and the evolution of services from custodial care to individualized support is protracted indeed. Significant effort at the federal, provincial, and local levels is needed if the service landscape in Canada is to continue to evolve towards support that is grounded in valued social roles, the exercise of collective and individual capacities, strong relationships, and the empowerment for people with developmental disabilities (Pedlar, Hutchison, Arai, & Dunn, 2000, p. 339).

Such a statement demands an investigation into some of the outcomes associated with the deinstitutionalization process as well as how it might be implemented more successfully. Deinstitutionalization itself represents a single case of the broader issue of environmental transitions for persons with ID. A person with ID may be expected to undergo a series of transitions throughout their lifetime from hospitals, family residences, group homes and even day programs or vocational placements within the same association. The execution of community placement and transition has varied and many “best practices” still need to be validated. Thankfully, there has been an abundance of research devoted to deinstitutionalization and

community living which can aid in illuminating the benefits and avenues for improvement inherent in such movements.

### *Deinstitutionalization Outcomes*

Outcome studies examining the effects of deinstitutionalization are diverse with regard to both their design and the variables under investigation. Typically measured outcomes are derived along five dimensions: choice/community integration, family contact, quality of life, as well as challenging or adaptive behaviour (e.g., Emerson & Hatton, 1996; Young & Ashman, 2004b). These outcomes, though treated as separate domains, are essentially interconnected as an impact in one area often has positive or negative consequences for habilitation in another. In this context habilitation encompasses improvement in functioning to the extent that an individual is able to live as independently as possible and experience a more normalized lifestyle (Bannerman, Sheldon, Sherman, & Harchik, 1990).

### *Choice and Community Integration*

The spheres of choice and community integration obviously overlap and are highly relevant to the fulfillment of the concept of normalization. Both suggest the possibility for engagement in activities that may have been denied or unavailable in an institutional setting. Many studies utilizing repeated measures designs have shown the benefits of deinstitutionalization for subjects' participation in community leisure and recreational activities (Cummins, Polzin, & Theobald, 1990; Dagnan, Ruddick, & Jones, 1998), vocational pursuits (Conroy, Spreat, Yuskauskas, & Elks, 2003), and general use of community services (Emerson & Hatton, 1996; Young, Sigafos, Suttie, Janene, Ashman, & Grevell, 1998).

Similarly, a variety of longitudinal studies have demonstrated the greater opportunities for the expression of choice in persons with ID living in the community (Janssen, Vreeke, Resnick, & Stolk, 1999; Stancliffe & Abery, 1997; Young & Ashman, 2004c). The improvements in these areas have often been associated with participants displaying higher levels of adaptive behaviours (Baker, 2007; Perry & Felce, 2005). As asserted by Janssen et al. (1999), "Living in the community is an important condition that forces caretakers to provide more freedom, more chances for training and development, and for integration" (p. 14). Despite this assertion, persons must first have the requisite adaptive skills to take advantage of these opportunities.

#### *Family Contact*

Since the deinstitutionalization movement itself was largely driven by the advocacy of family members it should come as no surprise that the involvement of family weighs heavily among the outcomes of community placement. Comparisons of pre- and post-deinstitutionalization data have demonstrated that both the opportunities for and frequency of family contact increases with movement to the community (Conroy et al., 2003; Cummins & Dunt, 1988; Cummins, et al., 1990b, Emerson & Hatton, 1996, Spreat & Conroy, 2002). Family involvement in the process itself has also been tied to positive outcomes (Causby & York, 1990).

#### *Quality of Life*

Enhancing the quality of life of persons with ID was one of the principle grounds for the movement toward deinstitutionalization. Quality of life (QOL) essentially implies reinforcing habilitation in a person's physical, material, social, productive, emotional and/or civic well-being

(Felce, 1997). These categories generally encompass the aforementioned dimensions of choice, community integration and family contact. Findings from early studies were usually inconsistent with both positive and negative outcomes observed (Cullen, Whoriskey, Mackenzie, Mitchell, Ralston, Shreeve, & Stanley, 1995; Hemming, Lavender, & Pill, 1981; Janssen et al., 1999). It has often been suggested that QOL outcomes vary depending on the type of measure in use (e.g., objective vs. subjective, mainstream criteria, etc; Allen, 1989). More recent studies utilizing objective QOL instruments have revealed considerable improvements in QOL scores following deinstitutionalization (e.g., in areas of community participation, social networks, activity levels, health, and access to services; Young & Ashman 2004a; 2004b; 2004c). Despite these trends QOL scores are usually not maximal and sometimes these increases are not maintained in the long-term (Young & Ashman, 2004a; 2004b). Reasons for this lack of maintenance might be connected to issues in service structures and supports as well as the individual characteristics and abilities of participants (Perry & Felce, 2005). Hence the promotion of QOL requires ongoing service refinement, education, and skill-building measures.

### *Challenging Behaviour*

Many persons with intellectual disability present with challenging or maladaptive behaviour. This can often prove troublesome in arranging for appropriate services and supports for individuals. Of the outcomes often studied in connection with deinstitutionalization challenging behaviour has shown the most variable results with levels increasing (Fine, Tangeman, & Woodard, 1990; Nottestad & Linaker, 2002; Nottestad & Linaker, 2001; Nottestad, Stromgren, & Linaker, 2000; Young et al., 1998), decreasing (Conroy et al., 2003; Emerson & Hatton, 1996; Molony & Taplin, 1988; Stancliffe & Hayden, 1998; Young, 2003) or



remaining stable (Kim, Larson, & Lakin, 2001; Lowe, et al., 1998; Molony & Taplin, 1990; Stancliffe, et al., 2002; Young et al., 1998; Young & Ashman, 2004b) post-deinstitutionalization. These inconsistencies can be related to a number of factors. As with the other outcome domains, “behaviour problems do not occur in a vacuum, are responsive to the environment, and can result from a shortfall in services rather than as a result of institutionalization or deinstitutionalization per se” (Young & Ashman, 2004c, p.407). Challenging behaviours themselves may prevent habilitation in other domains or be a factor of skill deficits (e.g. communication issues) and inadequate assessment. Although the literature remains uncertain with regard to what elements of deinstitutionalization specifically mediate challenging behaviour, research on behavioural interventions is clear in delineating effective proactive and positive approaches to treatment (Feldman, Condillac, Tough, Hunt, & Griffiths, 2002).

### *Adaptive Behaviour*

The adaptive behaviour or functioning of persons with ID and its concomitant effects or influences is interlaced throughout the previous dimensions. Given this detail it is important to consider the relation of adaptive behaviour to the deinstitutionalization process. The American Association on Intellectual and Developmental Disabilities broadly defines adaptive behaviour as, “the conceptual, social, and practical skills that people have learned to be able to function in their everyday lives” (AAIDD, 2008). The Association further states that, “Significant limitations in adaptive behavior impact a person's daily life and affect the ability to respond to a particular situation or to the environment” (AAIDD, 2008). Adaptive behaviour, then, may include a spectrum of abilities involved in activities of daily living such as self-care, communication, academic, occupational, and community living skills. Deinstitutionalization

represents a profound lifestyle change for persons with intellectual disability. Adaptive behaviour, as the AAIDD definition implies, may interact in a number of ways posing as either habilitative or detrimental throughout the process of transition and community placement. Greater adaptive skills have been correlated with the level of choice and community integration persons with ID experience following transitions to community settings and are directly related to the definition and measurement of quality of life (Kearney, Durand, & Mindell, 1995; McGrew, Bruininks, & Thurlow, 1992; Felce, 1997). Not only is there the potential for interactions between adaptive behaviour and other deinstitutionalization outcomes but there is also the possibility of variation across adaptive behaviours themselves.

Adaptive behaviours generally relate to the particular environment in which one is living. Institutional settings have been noted for their meagre range of services promoting functional independence for their inhabitants (Stancliffe & Hayden, 1998). Although resident's adaptive skills may be sufficient for the routine employed in the institution the environment virtually enchains people to a specific level of functioning offering few opportunities for growth and improvement. This situation is obviously incongruous with the principle of normalization which fosters the provision of services aimed at achieving a lifestyle more in line with choice and habilitation (Wolfensberger, 1972). Furthermore, measures of adaptive behaviour have been designed to approach this construct from a more normalized perspective of cultural conformity and human rights (Spreat, 1982). Thus, adaptive behaviour not only implies a set of accepted skills aimed at independent and functional living but also the opportunity to develop and express these skills. Deinstitutionalization itself represents such a chance however the supportive elements and ensuing environments themselves will largely dictate the extent of this opportunity.

Adaptive behaviour changes have been one of the more deeply studied areas of the deinstitutionalization process in North America and the U.K., with the caveat that the samples, focus and methods of study have varied considerably. Although diverse, most studies of adaptive behaviour have demonstrated at least modest improvements in adaptive skills.

A number of matched control studies have followed the progress of participants moving to the community while concurrently tracking their matched counterparts who remained at the institution (Cullen, et al., 1995; Lerman, Apgar, & Jordan, 2005; Molony & Taplin, 1990; Paré, Parent, Pilon, & Coté, 1996; Paré, Parent, Pilon, & Coté, 1994; Schroeder & Henes, 1978; Spreat & Conroy, 2001). Five of the 7 studies had positive outcomes related to adaptive behaviour with durations between baseline and follow-up ranging from 3 to 27 months. Most participants in these studies presented with severe or profound levels of ID (Lerman et al., 2005; Paré et al., 1996; Paré et al., 1994; Schroeder & Henes, 1978; Spreat & Conroy, 2001). Gains were generally related to self-care, daily living skills, communication and community integration (Lerman et al., 2005; Molony & Taplin, 1990; Paré et al., 1994; Schroeder & Henes, 1978; Spreat & Conroy, 2001). The remaining studies failed to show statistically significant changes in adaptive skills post-deinstitutionalization (Cullen et al., 1995; Paré et al., 1996). Although some institutionalized control group scores showed improvement with time these gains never rivalled those of participants who moved to the community. Another finding of note demonstrated that although general cognition did not increase for deinstitutionalized subjects it significantly decreased in those who stayed in the institution (Lerman et al., 2005).

Studies employing time-series designs with participants serving as their own controls displayed similar findings to those using matched control schemes with 9 of 10 studies exhibiting

improvements in adaptive behaviours (Conroy et al., 2003; Cummins & Dunt, 1988; Cummins, Polzin, & Theobald, 1990a; Dunt & Cummins, 1990; Fine, Tangeman, & Woodard, 1990; Jourdan-Ionescu, Ionescu, Corbeil, & Rivest, 1990; Kleinberg & Galligan, 1983; Walsh & Walsh, 1982; Young & Ashman, 2004b; Young & Ashman, 2004c). Participants were also typically in the severe to profound range of ID with measures extending as long as 5 years after moving to community residences. Similar enhancements in the areas of self-care, social, domestic, and communication skills were demonstrated (Cummins & Dunt, 1988; Dunt & Cummins, 1990; Fine et al., 1990; Kleinberg & Galligan, 1983). Young and Ashman (2004c) specifically examined adaptive behaviour changes across levels of ID. Post-deinstitutionalization scores were unchanged for persons in the mild to moderate range but significantly improved for participants with severe or profound ID (Young & Ashman, 2004c). There was also the recognition of the potential for a plateau effect following community placement with improvements levelling out after 2 years (Young & Ashman, 2004b). These findings suggest the need for individualized supports depending on the level of ID as well as continuing engagement in education and skill-building activities.

Although both matched-control and time-series analyses have revealed the prospect for habilitation in adaptive behaviours following deinstitutionalization these studies do not discriminate between the effects of different community environments. Some studies have investigated changes in adaptive behaviour in different community settings (Felce, de Kock, Mair, & Saxby, 1986; Lowe, Felce, Perry, Baxter, & Jones, 1998; Stancliffe, Hayden, Larson, & Lakin, 2002). Felce et al. (1986) compared the adaptive behaviour of 28 participants over a period of 18 months in group homes, small community-based institutions, and private family homes. Those residing in the group homes had more statistically significant improvements in

adaptive functioning than participants in the other settings. The greatest improvements were in the areas of independent functioning, domestic skills, and self-direction (Felce et al., 1986). Lowe et al. (1998) had comparable results with 41 subjects with severe ID in smaller community residences out-scoring hostel or hospital settings. However, family homes scored better than group homes in this study. Group homes were also associated with statistically significant increases in adaptive behaviour in the Stancliffe et al. (2002) study (which compared group homes to intermediate care facilities). The results of these studies suggest that adaptive skills are mediated by more than just the differences between community and institutional environments.

While the literature certainly suggests the beneficial aspects of community care there remain issues in the comparability and magnitude of improvements across studies. Not only did studies differ in sample size ( $n = 20-300$ ) but also in the design and instruments used to assess adaptive behaviour changes (Kleinberg & Galligan, 1983; Lerman et al., 2005). Over 10 different standardized and unstandardized instruments or measures were used throughout these studies (Cullen, et al., 1995; Cummins & Dunt, 1988; Jourdan-Ionescu et al., 1990; Lerman et al., 2005; Molony & Taplin, 1990; Paré et al., 1996; Paré et al., 1994; Schroeder & Henes, 1978; Spreat & Conroy, 2001; Stancliffe et al., 2002, Walsh & Walsh, 1982). The consistent positive results found across studies allow for some general conclusions to be made however the variation in magnitude of these effects across studies remains to be addressed. The influence of adaptive behaviour on the perceived success of the transition itself also continues to be unclear.

#### *Adaptive Behaviour and Meta-analysis*

Although some general conclusions can be made based upon a narrative review of adaptive behaviour outcomes associated with deinstitutionalization such a review is inherently

limited. The technique relies on a subjective analysis of the established findings and weightings that derive from researcher's knowledge of the subject matter rather than more objective criteria. While studies can be critiqued for their methodological and design weaknesses this process relies heavily on inferences made from the available information (Kavale & Glass, 1981). The primary limitation of narrative accounts lie in their inconsistency in standards of evidence across studies as well as the lack of a common metric with which to compare and contrast results (Kavale & Glass, 1981). A narrative review certainly reveals a trend for habilitation in adaptive behaviour following deinstitutionalization however the breadth of and variables affecting this trend remain largely hidden.

Statistical integration with the use of meta-analysis essentially fills these gaps. The technique of meta-analysis specifically satisfies 3 basic criteria,

(a) [The elimination of] bias in study selection – studies should not be excluded on arbitrary and a priori grounds; (b) [the usage] of all information - study findings should be transformed to commensurable expressions of magnitude of experimental effect or correlational relationship; and (c) [The detection] of statistical interactions – study features that might mediate findings should be defined, measured, and their covariation with findings studied (Kavale & Glass, 1981, p. 532)

To this end, Lynch, Kellow, & Wilson (1997) organized a meta-analytic study of adaptive behaviour based on studies examining samples of persons with ID having been deinstitutionalized. Lynch et al. (1997) were struck by the relative lack of quantitative data in this domain. Using the descriptors *deinstitutionalization* and *mental retardation* three databases were searched for relevant articles (ERIC, Psychological Abstracts and the Dissertation Abstracts International). The researchers also contacted Developmental Disability Councils across the

United States for material that met their inclusion criteria (Lynch et al., 1997). Of the 68 studies identified in this manner 11 met the final criteria:

1) the study utilized a minimum of six experimental subjects, 2) subjects were followed for at least nine months of community living, 3) adaptive behavior instruments were used to collect outcome data, 4) basic demographic and diagnostic data were reported, 5) subjects were exclusively adults, and 6) all outcome data were reported quantitatively (Lynch et al., 1997, p. 256).

These refined criteria were utilized in an effort to identify “stable, long-term studies of adults in deinstitutionalization programs” (Lynch et al., 1997, p. 256). These criteria are fairly representative of the data necessary for the completion of a characteristic meta-analysis but also illustrate the potential for bias in the selection of studies. For example, it could be argued that short-term effects of deinstitutionalization on adaptive behaviour are just as relevant in determining the interactive aspects of the process.

Concomitant with their selection criteria, Lynch et al. (1997) extracted a number of independent variables across demographic, methodological, and outcome domains. Fifty-one separate effect sizes were computed across the 11 studies with a mean  $\Delta$  of .43 ( $SD = .63$ ) (Lynch et al., 1997). Hence, deinstitutionalization was associated with an overall positive effect on adaptive behaviour. A homogeneity analysis was conducted revealing that the effect size distribution was heterogeneous. Three main findings pertaining to the research design of studies were noted. First, studies using matched-control designs displayed much larger average effects than those using own-control designs. Second, statistically significant differences were demonstrated between studies utilizing different assessment instruments. Finally, neither sample size nor follow-up length contributed significantly to effect size results. Lynch et al. (1997) also found that 4 of 6 adaptive behaviour domains (i.e., communication, academic, social and

community living skills) displayed similar average effects ( $M_d = .14-.21$ ). Both the self-care ( $M_d = .66$ ) and physical development ( $M_d = .05$ ) domains differed markedly from these values. On a subject level, higher adaptive behaviour effects were demonstrated in groups with severe/profound ID over those represented by all levels of ID (Lynch et al., 1997).

This study by Lynch et al. (1997) demonstrated the myriad of variables potentially interacting in the habilitative effects of deinstitutionalization on adaptive behaviour. These findings do indicate the potential for mediation of adaptive behaviour effects depending on the characteristics of the independent variables. The results across the domains of adaptive behaviour suggest that deinstitutionalization may bolster self-care skills simply through the provision of greater opportunity and responsibility inherent to community living. While the results in the other domains are positive their size may imply the need for greater supports in these areas after movement to the community. A similar argument might be made based on the findings centered on the level of ID of the participants in these studies. If, as shown by Lynch and colleagues, individuals with severe or profound ID have the potential for greater gains in adaptive behaviour after community placement the reasons for this effect must be expounded. These specific improvements might be due to a lack of opportunity and expression in the institutional environment or targeted supports and environmental features in the community. The Lynch analysis also indicates the variation in adaptive behaviour gains dependent on the type of instrument or measure. An interpretation might be made that some instruments potentially inflate or mask effects on adaptive behaviour. Such results will be based on the weighting some measures give to specific domains or items of adaptive behaviour. This either suggests the need for a more accurate definition of adaptive behaviour or the intentional use of measures that are better representative of an individual's treatment goals post-deinstitutionalization. These findings



certainly verify past research in this area and further point toward the benefits of deinstitutionalization. Although the Lynch meta-analysis has highlighted some of the specific factors that contribute to the habilitative effect of community living for adaptive behaviour a number of issues remain to be clarified.

Lynch et al. (1997) failed to report whether the average effect size of .43 was derived from analyses including or excluding identified outliers. If outliers were integrated in the calculation of this metric we can assume that the value is somewhat inflated (although the extent of this inflation remains unclear). Lynch and his colleagues also failed to account for the heterogeneity of their effect size distribution. The potential interpretational difficulties that arise from this limitation still need to be overcome with future analyses. Another matter worth noting is that Lynch et al. (1997) utilized Glass'  $\Delta$  in calculating effect size. Glass'  $\Delta$  estimates effect size using the standard deviation from the control group (rather than a pooled standard deviation as in Cohen's  $d$ ). Glass argued that this was a better method as effect sizes would not differ if there were equal means with different variances (Glass et al., 1981). Within the past decade Cohen's  $d$  has become the favoured method because of its popularity. This popularity stems from Cohen's categorization of small, medium, and large effects sizes, as well as a pooled estimate of standard deviation being more in line with the assumption of equal population variances (Thalheimer & Cook, 2002).

The continuing clarification of the effects demonstrated by Lynch et al. (1997) and their implications for clinical applications remains to be completed. Newer studies also need to be included in future analyses of this kind as the research base has expanded within the past decade. More importantly, initiatives to permanently close all institutions have made headway within the

past two decades along with more individualized service policies (Roehrer Institute, 1999). This is suggestive of a shift in practice, the results of which may be reflected in more recent studies on deinstitutionalization outcomes.

### *Applied Considerations and Social Validity*

The goal of meta-analysis with the use of the effect size statistic is to promote generalization across studies and examine the practical significance of treatment effects (Glass et al., 1981). In performing a meta-analysis Lynch et al. (1997) serve as detectives piecing together clues that illuminate how adaptive behaviour improves post-deinstitutionalization. While the results suggest some factors that may serve to hinder or bolster habilitation in this domain the practical consequences of these factors have yet to be specifically investigated. Though a number of specific definitions have been coined, social validity basically relates to the social importance and meaningful clinical significance of an intervention (Finn & Sladeczek, 2001). Such meaningful effects relate to fundamental changes in the individual presentation and lifestyles of participants who have been deinstitutionalized. The idea of what counts as meaningful change may vary considerably across participants and their service providers. As such, a recent ideological shift in the care of persons with ID, also relevant to deinstitutionalization, has been the development of individual lifestyle planning (ILP) models. This concept, also known as person-centred planning, frames interventions and care for persons with ID around the specific abilities and desires of the person in question (Mansell & Beadle-Brown, 2004). Any intervention goals or procedures are individualized drawing on the opinions and wishes of the person receiving care, her family and her care-providers (Mansell & Beadle-Brown, 2004). ILP has shown initial positive results in the context of deinstitutionalization identifying both

habilitative factors and obstacles to effective care (Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; Robertson, Emerson, Hatton, Elliott, McIntosh, Swift, Krinjen-Kemp, Towers, Romeo, Knapp, Sanderson, Routledge, Oakes, & Joyce, 2007; Robertson, Hatton, Emerson, Elliott, McIntosh, Swift, Krinjen-Kemp, Towers, Romeo, Knapp, Sanderson, Routledge, Oakes & Joyce, 2007). The ILP process represents a true measure of the practical significance of any intervention. In this way the intervention is made to fit the mould of the individual rather than attempting to force a “cookie-cutter” treatment on them. Hence, practical significance is made on a case to case basis. This model, though different, would seem to have a good fit within the framework and goals of a meta-analysis.

The degree to which ILP is utilized in transitions for persons with ID varies considerably across agencies and community associations. While not all aspects of transitions may be individualized it is still important to determine the types of supports and opportunities that have been provided and the extent to which these features have contributed to habilitation and success with the transition. Hundert, Walten-Allen, Vasdev, Cope and Summers (2003) completed a study for the purposes of identifying some of the features of the residential environment and the behaviour of persons with ID who moved from an institution to the community. Conducting an eco-behavioural analysis the authors demonstrated the relative importance of staff attention on participant behaviour. Challenging behaviours remained at institutional levels after moving to the community and this finding was largely tied to the fixed patterns of staff-participant interactions. Hundert et al. also acknowledged the greater opportunities to engage in social and leisure activities in the community. Although focusing on challenging behaviours this study showed that movement to the community in and of itself was not habilitative rather, it was the level of support provided. Such supports interact with individual abilities toward the expression of

functional independence in persons with ID. These supports and activities need to be continually assessed during and after transitions. Hundert and colleagues further acknowledged the value of individualized support plans in the behavioural adjustment of persons with ID. These elements need to be further analyzed in the context of clinical practice and community agencies for persons with ID.

Two studies examined different issues related to the efficacy and effectiveness of the deinstitutionalization and community transition process. In study 1, a targeted meta-analysis was conducted on deinstitutionalization adaptive behaviour outcomes. This study highlighted the numerous ways community placement affects habilitation in adaptive behaviour. The results of study 1 aided in the enhancement of a transition survey developed for the purposes of evaluating environmental transitions for persons with ID. Study 2 examined the piloting of this instrument in a sample of adults with ID who had recently been transitioned to the community from a Dual Diagnosis program at a Mental Health Centre in Ontario.

### Study 1

This study aimed to update and expand on the Lynch et al. (1997) study by conducting a targeted meta-analysis of adaptive behaviour outcome studies examining persons with ID who had been deinstitutionalized. This study allowed the inclusion of more recent studies in order to highlight current trends in deinstitutionalization and community living practices. Furthermore, the results demonstrated by Lynch and his colleagues were further qualified and the study's limitations accounted for. The analysis was directed toward outlining some generalizations for more effective and habilitative community services encompassing the aforementioned outcome dimensions (i.e., behavioural issues, community inclusion and quality of life). The meta-analysis

also informed the refinement of a transitional follow-up survey with the identification of important aspects of adaptive behaviour relevant to successful adjustment in the community.

## Method

### *Identification of Potential Studies*

The collection of studies for use in the meta-analysis was conducted in three distinct stages. The initial sample of studies was derived from the list used in Lynch et al. (1997). Upon identification of these 11 studies the second stage of compilation was undertaken. This stage involved an exhaustive search of three psychology databases, PsycARTICLES, Psychology: A SAGE full-text collection, and PsycINFO. These three databases were connected to a further six databases in conducting searches. These databases were chosen because of the specific psychological underpinnings of the aforementioned dimensions (i.e., quality of life, adaptive and challenging behaviour, etc.). These sources also allowed access to the dissertation abstracts and other non-peer-reviewed journal publications. Hence, a broader sampling of the deinstitutionalization literature could be conducted beyond peer-reviewed journal publications. Other publication databases such as Educational Resources Information Center (ERIC) and Medline were not utilized because of their non-behavioural and non-psychological focus. The combined searches resulted in 351 prospective journal articles using specific descriptors or keywords. The first search was conducted with the descriptors “deinstitutionalization” in the abstract and “behavior” listed anywhere within the document. This search produced 174 articles. A more refined search listing articles with both “community” and “adaptive behavior” (or “behaviour”) within the abstract identified a further 177 articles (154 using “adaptive behavior”

and 23 with “adaptive behaviour”). The third stage of article identification involved the visual analysis and screening of the accumulated articles based on selection criteria.

### *Sample Selection*

A visual analysis of the title and abstract of the 351 identified articles for potential adaptive behaviour outcomes associated with deinstitutionalization refined this number to forty-eight. The 48 articles were then screened based on specific selection criteria as outlined in Lynch et al. (1997):

1) the study utilized a minimum of six experimental subjects, 2) subjects were followed for at least nine months of community living, 3) adaptive behavior instruments were used to collect outcome data, 4) basic demographic and diagnostic data were reported, 5) subjects were exclusively adults, and 6) all outcome data were reported quantitatively (Lynch et al., 1997, p. 256).

An addendum to the Lynch et al. (1997) criteria was the requirement that articles contained relevant statistical data necessary to the computation of Cohen’s  $d$  effect size. Eight of the original sample of 11 studies used in Lynch et al. (1997) were found to possess the necessary data (Aanes & Moen, 1976; Close, 1977; Conroy, Efthimiou, & Lemanowicz, 1982; Eastwood & Fisher, 1988; Fine et al., 1990; O’Neill et al., 1985; Schroeder & Henes, 1978; Witt, 1981).

Similarly, 15 of the 48 articles identified met the selection criteria. (Conroy, Spreat, Yuskauskas, & Elks, 2003; Jourdan-Ionescu et al., 1990; Lerman, Apgar, & Jordan, 2005; Maisto & Hughes, 1995; Molony & Taplin, 1990; Paré et al., 1994; Rosen, 1984; Spreat & Conroy, 2001; Spreat, Conroy, & Rice, 1998; Stancliffe, Hayden, Larson, & Lakin, 2002; Walsh & Walsh, 1982; Young, 2006; Young & Ashman, 2004b; Young & Ashman, 2004c; Young, Ashman, Sigafos, & Grevell, 1998). As can be seen, 6 of the 15 studies identified were published before Lynch et al. (1997) and met their criteria but had not been included in their meta-analysis. Lynch and his

colleagues originally designed their criteria for the purposes of identifying studies that included a stable follow-up (i.e. at least 9 months). Only one of the studies identified for use in the present meta-analysis had a follow-up period less than 9 months (e.g., 6 months; Paré et al., 1994). This study was included as a number of studies have confirmed notable deinstitutionalization effects in as little as 3 months that were later shown to represent stable results (Lerman et al., 2005; O'Neil et al., 1985; Young et al., 1998).

### *Characteristics of the Sample*

The final 23 studies were published across 14 different journals (*Mental Retardation* (5), *American Journal on Mental Retardation* (4), *Revue Francophone de la Déficience Intellectuelle* (2), *Journal of Intellectual Disability Research* (2), *American Journal of Mental Deficiency*, *Australia and New Zealand Journal of Developmental Disabilities*, *Applied Research in Mental Retardation*, *Journal of the Association for Persons with Severe Handicaps*, *Research in Developmental Disabilities*, *Evaluation and Program Planning*, *The British Journal of Developmental Disabilities*, *Education and Training of the Mentally Retarded*, *Journal of Intellectual & Developmental Disability* and *the Dissertation Abstracts International*). Fourteen of the studies were American in origin, four were Australian, two Canadian and two originated in the U.K. The average year of publication for studies was 1992 (ranging from 1977-2006). A total of 1867 subjects participated in these studies with samples ranging from 15 to 263 subjects ( $M = 81.22$ ,  $SD = 66.03$ ). The average age of participants was 37.9 years ( $SD = 9.14$ ), however two studies were missing age data. On average the samples were 56.8% male ( $SD = 7.17$ ), with the exception of two studies missing such data. The level of intellectual disability varied across studies with 18 including participants with "All levels of ID" and 5 studies examining subjects

with severe or profound ID. All studies examined adaptive behaviour within the community. Participants in 15 studies resided in group homes or small, supported housing, 4 groups lived in intermediate care facilities, and 4 studies failed to discriminate as to the type of community environment. Thirteen studies used matched-control designs while the remaining 10 analyzed participants as their own control. Fifteen different adaptive behaviour instruments were utilized across studies. Follow-up periods across studies ranged from 6-60 months ( $M = 21.56$ ,  $SD = 17.52$ ).

### *Variables*

A total of 10 independent variables were coded from information extracted from the studies. Lynch et al. (1997) examined 6 variables in their analysis, intellectual functioning, sample size, follow-up interval, research design, instruments used, and outcome variables reported. The present study included these variables and four others. The variables in the present study were comprised of demographic (publication year, percentage male, mean age, disability level, and community setting), methodological (sample size, follow-up interval, and research design), and outcome variables (adaptive behaviour instruments and domains). These variables were selected in order to expand on the base of the Lynch et al. (1997) study and because they had well established mediating effects on behaviour (Landesman-Dwyer, 1981; O'Neill et al., 1985; Young & Ashman 2004c).

Publication year, sample size, the percentage of males in the study, mean age, years institutionalized and the follow-up interval were all coded as continuous variables in SPSS. More than half of the accumulated studies (13) had no data regarding the length of institutionalization for subjects. As such, this variable was subsequently deleted from the analysis.



The remaining variables represented categorical items and were coded as such. For level of intellectual disability 0 = All levels and 1 = Severe/Profound. Community setting was coded as 0 = home-style setting and 1 = other community setting. Research design was dichotomized as 0 = Own-control and 1 = Matched-control. The adaptive behaviour instruments (15), domains (9), and items (38) were similarly categorized. The domains of adaptive behaviour assessed included a global score, physical development, cognition, self-care, communication, academic, social, occupational and community living skills. After the initial coding stage all nominal variables were dummy coded for use in the eventual regression analysis.

### *Procedure*

Based upon the identified variables each study was divided into the number of possible outcomes to be computed. Cohen's *d* effect sizes were calculated from statistics reported in the studies. These usually took the form of means and standard deviations or *t* and *F* test statistics. *F* and *t* statistics were only appropriate when one degree of freedom was reported (Thalheimer & Cook, 2002). Effects were generated for eight domains of adaptive behaviour including a global score, self-care, communication skills, academic skills, social skills, physical development, community living/functional independence, occupational skills and cognition.

A number of studies used repeated measures of adaptive behaviour over the course of the research. Hence, multiple effect sizes were often computed for the same domain based on the duration between baseline and a given measure (i.e. self-care between baseline and 3, 6, 9, and 12 months of community living respectively). The average number of effects calculated for each study was 8.25 (*SD* = 7.78) ranging from 1-32.

### *Data-Analysis*

After the data file was appropriately coded it was screened for the purposes of identifying any missing or potentially aberrant data.<sup>1</sup> The variable “male percentage of sample” was found to be missing values non-randomly (4.1%). These missing values were recoded using group mean substitution across the “intellectual disability level” and “research design” variables (these being substantive variables in the analysis) (Tabachnick & Fidell, 2000). An outlier analysis was conducted identifying 6 multivariate outliers.<sup>2</sup> Outliers were also detected within each variable. Consequently, three variables were transformed to eliminate the outliers and achieve normality.<sup>3</sup> Five variables that could not be corrected with transformation subsequently had outlying values re-coded to 1 unit higher than the next highest non-outlying value (Tabachnick & Fidell, 2000).<sup>4</sup> Patterns of effects were then analyzed across research variables. These were determined by comparing average effect sizes across levels of categorical variables or conducting bivariate correlations between the Cohen’s  $d$  variable and all continuous variables.

A homogeneity analysis was performed on the Cohen’s  $d$  effect size distribution in order to determine whether all the effect sizes estimated the same population effect (Lipsey & Wilson, 2001). Inverse variance weights were first calculated for each effect size. The  $Q$  statistic was calculated for the distribution of Cohen’s  $d$  effect sizes. The assumption of homogeneity around a single parameter was rejected ( $Q = 327.1417$ ,  $df = 136$ ,  $p < .001$ ). Hence, the effect size distribution was heterogeneous.

A linear multiple regression analysis was conducted between the dependent variable of Cohen’s  $d$  effect size and the following independent variables: article publication year, the logarithm of study sample size, level of intellectual disability of sample, the square root of the

male percentage of the study sample, the square root of the follow-up interval for each study, and type of community placement environment. The assumptions for a linear multiple regression with this theoretical model were evaluated using SPSS 16.0<sup>5</sup>.

The assumptions were first evaluated in a linear multiple regression with the predictors against a set of random numbers and separately against the dependent variable. In conducting the multicollinearity analysis as part of testing the assumptions the variable “level of intellectual disability of sample” was found to have unacceptable multicollinearity, being too highly correlated with other predictor variables<sup>6</sup>. This variable was subsequently removed from any further analyses. The assumptions were confirmed again using the remaining variables<sup>7</sup>. Five multivariate outliers were detected based on their Mahalanobis distance values at a chi-square critical value of  $p < .001$ <sup>8</sup>. The extreme values in these cases were re-coded to 1 unit higher than the next highest non-outlying value as all cases were substantive to the analysis (Tabachnick & Fidell, 2000).

Multicollinearity and singularity were evaluated for the predictors using linear multiple regression analyses with random numbers and Cohen’s  $d$  effect size serving separately as the dependent variable with the identified multivariate outliers recoded<sup>9</sup>. No concerns were noted.

An evaluation of normality, linearity and homoscedasticity was performed with the identified multivariate outliers recoded<sup>10</sup>. All the assumptions for a linear multiple regression were met (Norusis, 2006).

Analyses were conducted in order to detect any potential moderator variables within the predictors<sup>11</sup>. One distinctive statistically significant moderator was revealed by the analysis. The

variable displaying the largest effect on the  $R$  value of the linear multiple regression, “logarithm of sample size mean centred by level of intellectual disability in the sample,” was chosen as the 7<sup>th</sup> and final predictor variable.

A final test of the assumptions was conducted for the final linear multiple regression model including the moderator variable and was found to be acceptable (Tabachnick & Fidell, 2000). No univariate or multivariate outliers were identified in the solution.

Although the assumptions for a linear multiple regression were met for the theoretical model the heterogeneity of the effect size distribution implied that a simple fixed-effects model could not be assumed and the outstanding variance needed to be accounted for. For the purposes of analyzing the heterogeneous distribution a fixed-effects model was assumed whereby variability beyond subject-level sampling error was systematic. In identifying the differences between studies that accounted for this variability a weighted linear multiple regression was conducted with Cohen’s  $d$  effect size weighted by the calculated inverse variance weights for each effect size. The inverse variance weights account for the differences in sample size between studies in calculating the effect sizes (Lipsey & Wilson, 2001). Corrected standard errors were computed for the B-weights in the regression results. The statistical software program was capable of conducting the weighted regression however it miscalculated the standard errors by misinterpreting the inverse variance weights as representing multiple effect sizes (Lipsey & Wilson, 2001).

The fail-safe  $N$  was calculated in order to detect the possibility of a publication bias for studies reporting statistically significant or positive results and to test the robustness of the

findings. The author selected a criterion value of  $d = .20$  ( $d_c$ ) based on Orwin's (1983) recognition of this criterion as representing a small or trivial value.

## Results

The average Cohen's  $d$  effect size across all studies and domains of adaptive behaviour was  $.40$  ( $SD = .36$ ,  $n = 136$ ). The average effect size between domains of adaptive behaviour varied (See Figure 1). Average findings in most domains approached medium positive effect sizes with the exceptions of communication skills and physical development which displayed very small average  $d$  values. Differences were observed in adaptive behaviour effects across levels of ID. Specifically, studies with participants representing all levels of ID had higher average effects ( $M_d = .44$ ,  $SD = .30$ ,  $n = 95$ ) than studies examining outcomes for persons with severe and profound ID ( $M_d = .30$ ,  $SD = .47$ ,  $n = 43$ ). This difference was statistically significant,  $t(137) = 2.25$ ,  $p < .05$ . Effects within the individual domains of adaptive behaviour also varied across levels of ID (See Table 1). Confirming the result observed in Lynch et al. (1997) studies utilizing matched-control designs resulted in higher average effects ( $M_d = .59$ ,  $SD = .35$ ,  $n = 66$ ) than those using subjects as their own control ( $M_d = .22$ ,  $SD = .27$ ,  $n = 72$ ). This difference was also statistically significant ( $t(137) = -7.02$ ,  $p < .001$ ). These results also fluctuated across adaptive behaviour domains (See Table 2). The observed effects in adaptive behaviour significantly differed depending on the type of community residence participants moved to ( $t(134) = 4.64$ ,  $p < .001$ ). Group homes displayed the highest average effect ( $M_d = .50$ ,  $SD = .34$ ,  $n = 89$ ) as opposed to undifferentiated or general community environments ( $M_d = .23$ ,  $SD = .31$ ,  $n = 47$ ). Effect sizes over adaptive behaviour domains also varied in relation to community setting (See Table 3).

The choice of adaptive behaviour instrument in measuring rehabilitative effects was also of interest. Fifteen different scales or instruments were used across the 23 studies. A statistically significant result was found from the one-way ANOVA on effect size as a function of adaptive behaviour instrument ( $F = 12.58$ ,  $df = 14, 124$ ,  $p < .001$ ). This variation in effect size across instrument type can be seen in Table 4. Specifically, a statistically significant one-way ANOVA was found for effect size as a function of whether the adaptive behaviour instrument was research-based or clinically-derived ( $F = 12.25$ ,  $df = 1, 137$ ,  $p < .001$ ). Higher average effect sizes were demonstrated for research-based ( $M_d = .48$ ,  $SD = .35$ ) rather than clinical instruments ( $M_d = .27$ ,  $SD = .34$ ).

Table 5 illustrates the correlations between the variables, the unstandardized regression coefficients (B) and the intercept, the standardized regression coefficients ( $\beta$ ), the semi-partial correlations ( $sr_i^2$ ),  $R^2$ , and the adjusted  $R^2$  (Tabachnick & Fidell, 2000, p. 164). A statistically significant finding was found for the regression,  $R = .685$ ,  $F(7, 128) = 16.164$ ,  $p < .001$ .

The results of the weighted linear multiple regression analysis and corrected standard errors for the B-weights are displayed in Table 6. This weighted regression was also statistically significant,  $R = .676$ ,  $F(7, 128) = 15.394$ ,  $p < .001$  with the LOG of sample size, research design, and the moderator variable (LOG of sample size by disability level) significantly predicting higher effect sizes.

The fail safe  $N$  based on a  $d_c = .20$  was found to equal 23 studies which exactly equalled the  $n$  in the present study. This verified the robustness of the results with an average  $d = .40$ .

#### *Application of Meta-Analysis Findings*

The meta-analysis findings suggested a number of areas that are important for the assessment of any community transition. The relatively low average effect size for communication skills and physical development suggested the need to examine the level and types of supports offered to persons with ID undergoing transition to the community. These issues may be further mediated by both the person's level of ID and the type of community setting to which they have moved. In particular, persons with severe or profound ID may require more individualized attention with regard to the provision of services and skill building activities, especially in relation to general cognition, self-care and communication skills. Although community living obviously promotes functional independence by providing opportunities for skill expression and development this does not negate the need to individually assess the types of services people are receiving or may require (e.g. speech and language pathology, occupational therapy, etc).

The statistically significant bivariate correlation between effect size and length of follow-up acknowledges the potential for greater gains and stability to be demonstrated the longer a person remains in the community in a supportive environment.

Although many of these issues were already expressed in some form on the Agency Transition Survey individual items targeting these specific features were added in the form of a Demographic and Supplemental Information Form (Appendix B).

## Discussion

The meta-analysis seems to confirm the habilitative effects of deinstitutionalization for adaptive behaviour in adults with ID. Despite this positive outcome, improvements across studies seem to be modest in most domains especially given the average effect size measure of  $d = .40$ .

The argument for what signifies a noteworthy effect size measure has been a hotly contested issue that is generally relative to the research area and method in use (Cohen, 1988). Considering the context of the previous meta-analysis conducted by Lynch et al. (1997) the present study has yielded similar positive effects (albeit in a different metric) associated with the transition of persons with intellectual disabilities from institutional settings to the community. Since Cohen's  $d$  will be less than Glass'  $\Delta$  when the standard deviation of the treatment group is larger than that of the control the present study may offer a more conservative estimate of adaptive behaviour changes than that shown by Lynch and his colleagues. The average  $d$  (.40) points to the general habilitative effects of moving to more normalized, less restrictive environments. Hence, there are some gains to be made with community living however these may be limited. The findings for the average effect size across domains of adaptive behaviour differ drastically from those found in Lynch et al. (1997). Of the domains covered in Lynch et al. (1997) only self-care displayed an effect size greater than .21 (.66) while all other domains achieved .21 or less. In the present study, only communication skills and physical development had an average effect size less than .30 (.13 and .12 respectively). These discrepancies can possibly be attributed to the service landscape that has developed in the past decade having shifted to actively promoting social skills and functional independence. Contrarily, some of the disparities in results between the studies may be the effect of different definitions for the domains of adaptive behaviour and the individual effects used to compute the averages. The lower average effect sizes observed in the domains of academic skills, physical development and



communication skills might be expected based on the population under study. Areas other than academic skills were probably the priority for service providers when these samples were younger. Added to the environmental limitations of the institutional setting it is not surprising that effects in academic skills are less than many of the other domains. Similarly, since the studies used in the meta-analysis were drawn from an adult population it is not unexpected that the transition had little effect on communication skills and physical development. These would likely be relatively static features across samples with little improvement without more intensive interventions (physical development and communication patterns likely stabilize to a certain degree by adulthood). This contrasts with the other domains of adaptive behaviour where habilitation may be the direct result of the design of the community setting fostering these developments such as functional independence, social skills, etc. Given these results, community service provision might place a greater focus on interventions aimed at maximizing communication skills and physical abilities (i.e. through the use of functional communication systems or occupational therapy).

The statistically significant differences in Cohen's  $d$  effect size across a number of the categorical variables also suggest some potentially mediating factors with community habilitation. Greater habilitation or effects were demonstrated for studies examining all levels of intellectual disability and samples taken from group home style placements (as opposed to samples with severe and profound ID and undifferentiated community settings). These results are both plausible from a developmental and research method standpoint (however the former finding conflicts with that found in Lynch et al., 1997). It is likely that samples with severe or profound ID were less able to adapt to the new environments than their counterparts in samples that featured participants with mild or moderate ID. The baseline skill level between the two

samples is likely to have differed accounting for some of the disparity. The statistically significant differences found between all levels of ID and severe and profound samples were limited to the domains of cognition, communication and social skills. The difference observed in the social skills domain is difficult to interpret given that the average value in the severe or profound category is based upon a single study with a single effect. This study, by Close (1977), is noteworthy for its utilization of intensive behavioural interventions in the new community environment (i.e. individualized skill training programs, consistent behaviour management and program evaluation methods). It is possible that the large effect observed in this study was mainly a result of these techniques which may not be present in community placements highlighted in other studies. The discrepancy between effects in the areas of communication skills and cognition suggest the need for more targeted interventions for persons with severe and profound ID. These findings may also point toward general functional limitations in this group that preclude larger effects. Lynch et al. (1997) did not specifically distinguish between domains of adaptive behaviour and relative effects for samples with severe/profound subjects versus those with all levels of ID. The disparity between the Lynch et al. (1997) study and the current one in this respect is present despite the fact that both studies had a roughly similar proportion of studies examining samples with only severe or profound ID (3 of 11 versus 5 of 23).

The greater effects demonstrated in group home style settings might be explained by a number of factors. These include the types of individuals they tend to accept, the structure of these programs and the types of skills they tend to reinforce, or the quality of staff and accompanying services. Regardless of which of these influences exert more of an effect on habilitation, it seems appropriate that group-home style settings should be promoted in favour of

larger, intermediate care facilities (which accounted for a number of the general community placement types).

In finding that matched-control research designs had significantly higher effects than own-control (or repeated measures) designs the present study both confirmed the previous findings of Lynch et al. (1997) and offers a further avenue of analysis. In accounting for these results there are two probable influences both of which are implicitly tied to methodology. First, matched-control design may show greater effects due to the larger skill disparity or decline of control samples that remain in the institutional environments. As a case example of this, Stancliffe & Hayden (1998) examined the 4-year longitudinal effects of continued institutionalization on 71 adults with ID. The authors found that continued institutionalization was associated with statistically non-significant decreases in adaptive skills. It is also important to consider that there may be particular reasons why the control samples were chosen to remain in the institution (e.g. more challenging behaviours, medical or psychiatric conditions, etc.). Second, and as a function of the first, samples that serve as their own controls may not have as much room for improvement thus limiting the potential rehabilitative effects. Future research might address these issues.

The findings across the types of adaptive behaviour instruments used within the included studies also reflected the potential for interpretive difficulties regarding any rehabilitative effects. The average effect size varied considerably based on the type of instrument used. Some averages were based on only 1 calculated effect size from a study while others were derived from up to 50. It is difficult to judge whether these results suggest specific sample or psychometric influences. The finding that research-based or standardized instruments typically found higher

overall effect sizes than clinical instruments suggests that inherent differences between these may contribute to some of the variation found. Future studies will have to be conducted in comparing scores across instruments with a similar sample. For the time being the results derived from the research-based instruments might be trusted as a more accurate reflection of adaptive behaviour gains following deinstitutionalization (given their relatively strong psychometric properties and design elements).

A number of the aforementioned findings were confirmed by the weighted multiple linear regression. Larger effect sizes were significantly predicted by the sample size and research design of each study. Hence, studies with larger sample sizes and matched-control designs were found to have more sizeable adaptive behaviour effects. The moderator variable, sample size by level of intellectual disability also significantly predicted greater effects. "Level of intellectual disability in sample" moderated the degree of relevance "sample size of study" had on Cohen's  $d$  effect size such that sample size was more relevant to the Cohen's  $d$  calculations when the sample was composed of persons with severe to profound ID versus samples composed of all levels of ID. These results are useful in the interpretation of studies examining adaptive behaviour gains for persons with ID post-transition. When considering these studies the size of the effect must be weighed in relation to the study design and methodology. Thus, in the case of adaptive behaviour studies, larger effect sizes may be more meaningful in own-control studies with smaller sample sizes representing participants with various levels of intellectual disability. In these cases large effects are less expected than studies with the opposite characteristics. Because of this, the effect may be more representative of actual adaptive gains versus an artefact of the study features.

Despite these promising outcomes there are a number of limitations inherent to the present study. The meta-analysis has three primary concerns. First there is the issue of the study selection criteria. The selection criteria for studies used in the meta-analysis consisted of several components. Only 3 psychology databases were specifically examined for the purposes of identifying potential studies. This was done for specific theoretical reasons but certainly limited the potential identification of some studies. Furthermore, the identification of potential studies within these databases was dependent on the types of keywords used in the search. It is possible that other relevant articles exist outside of the 3 databases or utilize unique keywords in their titles or abstracts. The use of Lynch et al. (1997) as the basis for the meta-analysis may also have limited results or their interpretation especially if other meta-analyses had been conducted in this topic area using different methods or articles. Unfortunately, issues related to time constraints and the available resources at the researcher's disposal precluded a more thorough review of other databases or keyword combinations. Future efforts could be taken to mediate these weaknesses.

Second, the way adaptive behaviour measures were categorized across studies needs to be considered. The domains used in the present study represented an amalgamation of various outcomes found throughout the identified studies. Hence, items such as eating, toileting and hygiene were all classified as self-care activities with effect sizes for each of these items used in the computation of the average effect for self-care. Similar methods were used for other domains (e.g. social skills, social interaction, and socialization etcetera being lumped together into a "social skills" domain). These categorizations were all determined based on definitions created for the purposes of this study<sup>12</sup>. The resulting effect sizes might be inflated or reduced in these domains depending on the definitions used across studies. Although a number of domains were

relatively clear some (such as self-care and community living/ functional independence) were closely related. While it is unknown what definitions were originally used in the Lynch et al. (1997) study the consistent use of the defined domains in this study should render valid results.

Once the dataset was constructed a number of analysis decisions affected the resulting characteristics of the collected studies and variables. Two studies had two or more variables collapsed and averaged in order to fit within the assumptions of normality and preclude outliers or inconsistencies that could have misrepresented the results. Similarly, a number of variables were transformed, missing values substituted (using methods such as group mean substitution), and values altered to fit underlying assumptions. Although all of these steps were necessary for the completion of the final analysis and supported by the available literature not all of the steps were optimal (Tabachnick & Fidell, 2000). These limitations largely represented a compromise between the needed steps to permit an appropriate analysis as well as the available resources or methods in the researcher's skill set.

The present meta-analysis has served to further develop the goals and findings of the Lynch et al. (1997) study as well as provide an expanded and more recent analysis of the studies in this domain. Continued meta-analyses of behavioural outcomes are important in gaining a broader picture of the field and informing future studies of the transitional experiences of persons with ID. The present study was able to confirm a number of results found by Lynch and his colleagues, especially those relating to the higher effect sizes associated with matched control designs and the variation in effects across different adaptive behaviour instruments. The inclusion of more and more recent studies in the analysis also provided more current and representative findings in adaptive behaviour gains following deinstitutionalization. While it is

not surprising that gains were made the pattern of habilitation may offer further avenues for research and clinical application. Specifically, the identification of adaptive behaviour domains that tended to show fewer improvements following deinstitutionalization (communication skills especially) may suggest the need for more research on these domains to identify the reasons behind these deficits. Similarly, these findings suggest the need for clinical intervention in such domains in order to foster habilitation. The pattern of habilitation across domains of adaptive behaviour in this study differed markedly from the Lynch et al. (1997) study. It appears that something within the service landscape, research samples or study designs has contributed to greater effects being demonstrated across domains of adaptive behaviour. The addition of the weighted linear multiple regression to the present analysis (given the effect size distribution's heterogeneity) adds to the validity of the findings and furthers the analysis beyond that conducted by Lynch et al. (1997). This regression confirmed Lynch et al.'s (1997) finding of the influence of a study's research design (e.g. matched-control versus own-control) on the effect size. Similarly, the statistically significant moderator variable, sample size by level of intellectual disability, may explain some of the current results. In the present case, studies limited to severe and profound ID samples had lower average sample sizes than those including all levels of ID ( $M_d = 37.95$ ,  $SD = 46.89$  and  $M_d = 64.19$ ,  $SD = 35.96$  respectively). Hence, the influence may have been counterbalanced by this fact. The discovery that sample size was still a statistically significant predictor for larger effect sizes even after weighting the regression by sample sizes across studies points toward the importance of interpreting effect sizes contextually. A study with a sample size of 40 and an effect size of .50 may be just as meaningful as a study with an effect size of .60 ( $n = 125$ ).

Finally, the present study demonstrated numerous clinical interpretations and applications of its findings which is an improvement over the Lynch et al. (1997) study which focused little on these aspects. This is important for any meta-analysis given the procedures' aim of generalization across studies and evaluating the social validity of findings (Glass et al., 1981).

In the future, meta-analyses should also be conducted in other relevant transition domains (e.g. challenging behaviour, quality of life, family contact, etc). Such analyses might aid in providing a clearer picture of the transition experience for people with ID and suggest further recommendations for service provision and supports in community environments.

## Study 2

This study involved an analysis of the transitional process in a program/agency serving persons with a Dual Diagnosis. A transitional follow-up survey was piloted in a Dual Diagnosis Program in order to analyze both the transitional process and validate the instrument for use in transitions for adults with ID. Survey findings were used to evaluate the efficacy of the transition survey for the effective evaluation of deinstitutionalization and ongoing transitions for persons with ID. Specifically, the richness and sufficiency of the information provided were critically analyzed.

## Method

### *Participants and Setting*

Participants were drawn from agencies serving former clients of the Bayview Dual Diagnosis Program (BDDP) at the Mental Health Centre Penetanguishene. This facility is run under the auspices of the Catholic Health Association of Ontario. This program



is a client-centred specialty care program. The 25-bed inpatient treatment unit offers psychiatric assessment and treatment to individuals with a developmental disability and mental health problems. The program offers a continuum of multidisciplinary team services, including: referral, consultation, inpatient assessment, treatment/stabilization and outpatient community follow-up (Centre for Addiction and Mental Health, December 2005, p. 33).

The BDDP was ideal due to its connection with a number of community agencies for persons with ID, its involvement with supported, individualized community transitions and a clientele base which featured a number of persons with a history of institutionalization. The Agency Transition Survey was also thought to fit well within the program's Multidisciplinary Transition Discharge Model (Bayview Dual Diagnosis Program, 2007).

Participants included 8 staff members from community agencies serving former BDDP clientele. These staff members were direct care workers or behaviour therapists who had supported the identified clients since their transition to the community environment and were familiar with their presentation and histories. Six of the participants were female and 2 were male. All participants had close involvement with the community transition of one of the identified clients. Due to the nature of the study design no other characteristics were known about the staff members completing the surveys.

### *Measures*

The Agency Transition Survey (ATS) was developed by Faculty at Brock University for the purposes of assessing the elements and supports involved in community transitions for persons with ID (See Appendix A). This questionnaire asked proxy respondents to comment on the implementation and outcomes associated with a transition. It tapped into 6 specific domains: adjustment/adaptation, setting and supports, daily routines, activities and community inclusion,

changes since transition, and quality of life. While these domains did not directly speak to adaptive skills many of them were closely related to the typical areas assessed in studies on adaptive behaviour and deinstitutionalization (i.e. community living, functional independence, self-care, social, and occupational skills). The survey was designed to be completed by 2 individuals working together to gain a consensus on the transitional outcomes. The persons completing the survey should have known the client well and have been involved in different aspects of the implementation and support of the transition. If the respondents could not reach agreement on a specific issue this was to be noted on the form. The Agency Transition Survey had not previously been validated and its reliability had not been verified across respondents.

The Demographic and Supplemental Information Form (DSIF) was derived from the meta-analysis on deinstitutionalization adaptive behaviour outcomes (See Appendix B). It addressed areas that were pertinent to the evaluation of the community transition and adaptive behaviours that had not been addressed in the Agency Transition Survey. It was a short form and briefly examined the domains of client demographics, adjustment, self-care, communication, and outstanding needs/supports. This form was designed to be completed in tandem with the Agency Transition Survey. The DSIF had not been previously used in any analysis and had yet to be field tested in conjunction with the Agency Transition Survey.

A Critical Analysis Tally Sheet (CATS) (See Appendix C) was also used in the evaluation of the usefulness of the data derived from the Agency Transition Survey and Demographic and Supplemental Information Form. The 41 criteria used in the tally sheet related to the 5 deinstitutionalization outcome dimensions and the bio-psychosocial model (41 criteria in 8 domains). This instrument identified whether the criteria were tapped by any of the items on

the ATS or DSIF. Thus the tally sheet yielded a score for how well the instruments corresponded to the criteria (out of 41). The number of criteria in each domain ranged from 2 to 10.

### *Procedure*

The Program Coordinator from the BDDP invited the author and his Faculty Supervisor to pilot the Agency Transition Survey along with the Demographic and Supplemental Information Form. The Program Coordinator provided the author with a list of all BDDP clientele who had been discharged between December 2006 and January 2009. Contact information for the agencies serving these discharged clients was collected from the patient files at the Mental Health Centre Penetanguishene. The author personally contacted the managers of the prospective agencies/homes, where former Bayview clients had moved, and inquired as to their interest. Twenty-eight agencies or homes were contacted in this manner. Of these, 20 expressed interest in participating in the study. Interested managers at the agencies received substitute decision maker consent forms and plain language client consent forms (See Appendix D & E) from the author to give to the clients (or substitute decision makers) about whom the staff members were being asked to comment. Client consent to the release of information was obtained before staff members were asked to consent to complete the surveys. Letters of invitation and consent forms were then forwarded to the managers for completion by staff members involved with the daily care and support of the previously identified clients (appropriate staff members were identified by agency/home managers). The surveys were sent out with a list of instructions both for managers and the staff members completing them. The instructions for the managers outlined the identification of appropriate staff/cases, distribution and collection of consent forms, timelines for survey completion, and the feedback they would

receive after the study had concluded (See Appendix F). Instructions for participants (included in the consent form) described steps for the proper completion of the survey forms as well as ways of contacting the author if they had a question regarding the procedures. Identified participants received a letter of invitation and consent form from their managers (See Appendix G & H). Staff members who chose to consent sent these forms to their manager (in sealed envelopes) who forwarded them on to the research supervisor. Upon consenting participants were given a copy of the ATS and DSIF and were paired with another staff member who had consented and was similarly involved in the transition of interest. Participants were asked to coordinate with their paired counterpart in completing the forms and acknowledge any areas where a consensus could not be made (by highlighting the appropriate question or writing two distinct comments). Participants were given 3 weeks to complete the surveys and return them to their manager (in sealed envelopes). The manager then sent them to the research supervisor. Surveys were coded (numbered) in order to remove any participant identifiers.

After receipt of the completed forms the author critically analyzed both the ATS and DSIF along with the answers provided by the respondents.

### *Data Analysis*

The ATS and DSIF were critically analyzed from a bio-psychosocial perspective based on the 5 dimensions of community adjustment (choice/community integration, family contact, quality of life, and challenging or adaptive behaviour). This analysis entailed comparing the information provided for each client to the established outcome variables in each dimension:

*Community integration and Choice:* The survey renders information relating to the use of community services, level of community integration or contact, types of choices available and level of expression on the part of the client, and the types of recreational or occupational activities engaged in (Conroy, Spreat, Yuskauskas, & Elks, 2003; Cummins & Dunt, 1988; Cummins, Polzin, & Theobald, 1990b; Dagnan, Ruddick, & Jones, 1998; Young, Sigafos, Suttie, Janene, Ashman, & Grevell, 1998; Stancliffe & Abery, 1997; Young & Ashman, 2004c).

*Family contact:* The survey renders information relating to the frequency of contact (both in and outside the home), level of involvement/advocacy on the client's behalf, and types of events/activities associated with family contact (Causby & York, 1990; Conroy et al., 2003; Cummins & Dunt, 1988; Cummins, et al., 1990b, Emerson & Hatton, 1996, Spreat & Conroy, 2002).

*Quality of life and well-being:* The survey renders information relating to effects in the person's global, physical, material, social, productive, and/or civic well-being (Felce, 1997). Objective information or ratings of the person's community participation, social networks, activity levels, health, level of support, and environment quality (Young & Ashman, 2004a; 2004b; 2004c).

*Challenging behaviour:* The survey renders information relating to changes (increases, decreases or stabilization) in the presentation and expression of pre-existing or developing forms of challenging behaviour (e.g., physical aggression toward others; Feldman, Atkinson, Foti-Gervais & Condillac, 2004).

*Adaptive behaviour*: The survey renders information relating to changes (increases, decreases or stabilization) in the presentation and expression of pre-existing or developing forms of adaptive behaviour (e.g., self-care skills; Conroy et al., 2003; Cummins & Dunt, 1988; Cummins, Polzin, & Theobald, 1990a; Dunt & Cummins, 1990; Fine & Tangeman, 1990).

The analysis was further clarified by discerning whether the ATS and DSIF provided useful information for the purposes of a bio-psychosocial assessment. The importance of a bio-psychosocial perspective was in judging whether the information relating to the 5 outcome dimensions was mediated or influenced by various biomedical, social-environmental, or psychological factors (Griffiths & Gardner, 2002). The areas of assessment for the integrated bio-psychosocial model included:

BIO (medical) – medical, psychiatric, medication reactions, syndromes neurological state. PSYCHO (logical) – current psychological features and skill deficits. SOCIAL – environmental, interpersonal, programmatic, physical (Griffiths & Gardner, 2002, p. 87).

These criteria were evaluated for each survey using the critical analysis tally sheet. The CATS was scored using a binary system (i.e., with individual criteria scored as “met” or “unmet”). Hence, the final score derived from this instrument described the total number of criteria met by the ATS and/or DSIF. Finally, a random sample of 8 questions was chosen to evaluate the quality of the information provided (i.e., the information was rich and sufficient enough to answer the question).

## Results

The ATS had questions relating to 32 of the 41 criteria. The DSIF met an additional 3 criteria. Hence, in combination the ATS and DSIF accounted for 85% of the community adjustment and bio-psychosocial criteria. Criteria that were not directly tapped by the forms included information relating to occupational activities, the material well-being of clients, the form or duration of any challenging behaviour, when changes occurred in challenging behaviour, and medications/side effects. Forty-seven of the seventy-one items on the ATS directly related to the established criteria. Similarly, criteria were linked to 9 of 15 items on the DSIF. The 6 items on the DSIF that did not correspond to the criteria provided supplementary information aiding in the analysis of transition outcomes (e.g., age, length of residence, barriers to receiving recommended supports, etc). The items not tapping into the criteria on the ATS also served a tangential function (e.g., relating to adjustment level, staff training, recommendations from the transition plan, etc). Twenty-one items in the ATS overlapped with more than one criterion. Seven items on the DSIF displayed similar overlap. As can be seen in figure 2, the ATS and DSIF generally met high proportions of the criteria in each domain. Only the domain of challenging behaviour was covered less than 80% by the ATS and DSIF. Figure 3 displays the proportion of each section of the ATS that directly corresponded to the criteria. All domains had had least 40% of their questions directly relating to the established criteria (4 of the 6 domains had greater than 60% correspondence).

Only 4 surveys/forms were completed and returned in the study timeframe. Hence, 4 pairs of subjects (8 total participants) participated in completing the forms commenting on the transitions of 4 clients. This represented 20% of the initial sample that expressed interest and received the survey packages. The results of the random sampling of 8 questions can be seen in table 7. Only three of the responses were insufficient in answering the question as stated (e.g.,

response 2 to ATS #2 and #59 and response 4 to ATS #59). Responses 2, 3, and 4 to ATS #66h were left blank however this was an optional question answered only if it was specifically applicable (which it obviously was not in these cases). The richness of the responses varied however a few answers proved somewhat limited or remained relatively ambiguous (e.g., response 2 ATS #2 and DSIF #8 as well as response 1 to ATS #38 and 68). Overall, 89% of the responses were sufficient in answering the question and 86% were rich enough to offer direction to an evaluation of the transition (e.g., response 2 to ATS #11 points to the need for either in home mediation between residents or examining the possibility of a different community placement).

### Discussion

Given the 85% correspondence rate between the ATS/DSIF and the community adjustment and bio-psychosocial criteria the usefulness of these instruments in evaluating transitional outcomes would seem to be justified. Future refinement of the ATS and DSIF could be directed toward developing questions that tap into the outstanding criteria. The reasons for these outstanding criteria could be related to the original intentions behind the development of the ATS and its use as one assessment in a more comprehensive package.

The attrition rate of 80% across the initial sample that received survey packages precluded any statistical analyses of the data. The attrition rate may have been due to the relatively short timeframe in which to complete the survey procedures or disinterest stemming from the commitment required in completing the forms. It is possible that further surveys may be returned outside the timeframe initially proposed. Based on the random sample of answers to the ATS and DSIF questions it would seem that respondents generally provided sufficient



information. The richness of the responses was also generally of high calibre. Instances of answers that were neither rich nor sufficient might be explained by limitations in knowledge on the part of respondents, missed questions or haste in answering the questions.

With regards to the piloting of the ATS and DSIF, four primary limitations deserve note. Although the survey itself was relatively broad in its scope regarding the assessment of the transition and the client's eventual adaptation it still neglected some areas that are relevant to the transition process for persons with ID. A transition cannot be judged in isolation; comparisons must be made to the individual's baseline level of functioning and other individual client characteristics (e.g. demographic variables, specific skills, as well as tapping into the opinions of other stakeholders in the process such as the client and his or her family members). Similarly, the features noted in the individualized transition plans (when they existed) or the plans themselves were not available to the researcher. These plans may have served as useful tools in the assessment of the success of the transition and getting a clearer picture of the client/placement fit. The survey itself was also only piloted within a small area of the developmental service sector in Southern Ontario. Only a few specific agencies were involved and then only a few surveys within each agency. Finally, no reliability checks were completed on the scoring of the ATS and DSIF using the CATS. These limitations at the very least call for an expanded research base using this instrument. Future research efforts could aim at expanding the use of the ATS and DSIF to a wider sample of sufficient number to examine the statistical qualities of the forms. While the present analysis has briefly touched on issues relating to validity a much more thorough statistical analysis is required.

#### General Discussion and Conclusion

Deinstitutionalization is a complex example of an environmental transition for persons with intellectual disabilities. Adults with ID can expect to experience a number of environmental changes within their lifetime. These may range from something as simple as changing their bedroom to moving to a completely new home in an unfamiliar community. This poses a challenge since persons with ID often have problems in flexibly adjusting to new environments or routines (Didden, Sigafos, Green, Korzilius, Mouws, Lancioni, O'Reilly, & Curfs, 2008).

Study 1 has certainly suggested the potential habilitative effects of community living for adults with ID. Although this study has identified a few of the variables relating to and predictive of these effects further research is needed to pinpoint specific individualized and service-based factors that aid with habilitation. Improvements related to community living do not occur in isolation. Both study 1 and previous studies have demonstrated that there is a dynamic interplay between person-specific, environmental, and methodological variables. If the developmental service sector landscape is to continue to evolve agencies for persons with ID and governments will need to be responsive to research findings in this area. Study 2 has demonstrated that the Agency Transition Survey and Demographic and Supplemental Information Form may be useful tools in the process of evaluating individualized transitions for adults with ID.

Although deinstitutionalization is nearly complete in many countries and provinces, the challenges associated with appropriately and respectfully caring for persons with ID still largely remain. The current service paradigm demands not complacency but action and refinement. Further research is needed to reveal and optimize best practices in transitions and services for people with intellectual disabilities.

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## Footnotes

<sup>1</sup> All continuous variables were explored in SPSS 16.0. Three variables were found to have missing values (“years institutionalized” 58% of individual effect size calculations missing, “mean age of sample” 13.8% and “male percentage of sample” 4.1%). The variable “years institutionalized” was deleted from the analysis as the available data did not permit a representative analysis of the variable across studies. After conducting crosstabs on these variables it was revealed that all missing values were missing non-randomly, which is problematic. One study (case 121) was subsequently collapsed across missing values and the effect sizes were averaged. This resulted in “mean age of sample” missing 10% of values non-randomly. Missing values in “mean age of sample” and “male percentage of sample” were re-coded using group mean substitution as none of the other variables were thought to be suitable predictors for use in a linear regression to supplement missing values.

<sup>2</sup> A linear regression was conducted using the continuous predictor variables with “Cohen’s  $d$ ” calculations as the dependent variable. Mahalanobis and Cook’s distance values as well as the leverage of each case were compared. This analysis revealed 6 multivariate outliers with Mahalanobis distance values that were greater than the statistically significant Chi-square values ( $p < .001$ ). Three other continuous variables also had identified univariate outliers (“male percentage of sample”, “sample size” and “follow-up interval”).

<sup>3</sup> Three variables were transformed in order to correct for the assumption of normality (“sample size”, “mean age of sample” and “follow-up interval”). The gentlest transformations possible were used with each variable to correct for problematic skew, kurtosis, and/or outliers. Computing the LOG of “sample size” corrected for all problems. Similarly, the inverse of “mean

age of sample” was performed. Finally, the square root of “follow-up” interval permitted the variable to be within acceptable bounds for normality assumptions.

<sup>4</sup> No transformations adequately corrected the issues for the variable “male percentage of sample.” Two cases in one study (cases 23 and 24) were collapsed and effect sizes averaged in order to correct for outlying values. In order to approach normality this variable had other outliers approaching 3 standard deviations from the mean re-coded. A similar procedure was conducted for the variables “Cohen’s  $d$ ”, “Inverse variance weights”, “Weighted Cohen’s  $d$ ” and “Weighted Cohen’s  $d^2$ ”. This procedure was used as all cases were still relevant to the analysis and their deletion would have seriously undermined the representativeness of the final analysis.

<sup>5</sup> The ratio of cases to the number of independent variables was calculated to determine whether an acceptable number of cases were present to validate the use of 6 independent variables (Tabachnick, B.G., & Fidell, L.S., 2000, p.163). The liberal calculation resulted in a requirement of 48 cases while the more conservative calculation required 120 cases. In the present analysis,  $n = 136$ , hence, the ratio was within bounds.

<sup>6</sup> Level of intellectual disability in sample and type of community placement environment were highly correlated ( $r = .736$ ).

<sup>7</sup> The normality, linearity, and homoscedasticity were evaluated for the residuals resulting from the linear multiple regression with random numbers as the dependent variable and the six predictor variables. Normality was assured as the coefficients of skew (-.071) and kurtosis (-.379) were both less than 1. Linearity was evaluated across all independent variables by plotting them and the unstandardized predicted values against the standardized residuals from the

regression. The lack of an increasing or decreasing trend in the scatterplot of the unstandardized predicted values against the standardized residuals also indicated an absence of homoscedasticity. Subsequent to evaluating the assumptions of the regression on a variable of random numbers the assumptions were tested against the proposed dependent variable, Cohen's *d* effect size. Normality was similarly confirmed with coefficients of skew (.627) and kurtosis (.045) within bounds. The assumption of linearity was also confirmed. Homoscedasticity was also absent based on the scatterplot between the unstandardized predicted values and the standardized residuals. Hence, the assumptions were met for the linear multiple regression for this model (Norusis, M.J., 2006, p. 221).

<sup>8</sup> The data were evaluated for any potential multivariate outliers using a chi-square critical value of  $p < .001$  which identified cases with a Mahalanobis distance on random numbers of greater than 22.458 as problematic outliers. Six cases were identified in this manner (sequential ID numbers 102, 103, 102, 113 outcome 1, 113, outcome 2, and 118). All six cases also had problematic leverage (i.e. 3 times the average leverage value of .098) (Tabachnick & Fidell, 2000).

<sup>9</sup> Multicollinearity and singularity were assessed for both the regression using random numbers and the regression with Cohen's *d* effect size as the dependent variable respectively. This was conducted after the identified multivariate outliers had been recoded. Correlations were computed between all of the independent variables and none of the variables utilized in the theoretical model had correlations  $r > .70$ . The values for the collinearity statistics were also confirmed for each regression (i.e. Tolerance  $> .5$  and VIF  $< 2.0$ ) (Tabachnick & Fidell, 2000). Each regression was evaluated for its collinearity diagnostics based on the value of the condition

indexes in the variance proportions on each model dimension row (i.e. greater than .3 across 2 consecutive variance proportions indicated a concern) (Tabachnick & Fidell, 2000). No variables had concerning collinearity. There were no perfect correlations between any of the independent variables hence no singularity was present in the independent variables (Tabachnick & Fidell, 2000).

<sup>10</sup> The normality, linearity, and homoscedasticity were evaluated for the residuals resulting from the linear multiple regression with random numbers as the dependent variable and the six predictor variables. Normality was assured as the coefficients of skew (-.071) and kurtosis (-.404) were both less than 1. Linearity was evaluated across all independent variables by plotting them and the unstandardized predicted values against the standardized residuals from the regression. The lack of an increasing or decreasing trend in the scatterplot of the unstandardized predicted values against the standardized residuals also indicated an absence of homoscedasticity. Subsequent to evaluating the assumptions of the regression on a variable of random numbers the assumptions were tested against the proposed dependent variable, Cohen's *d* effect size. Normality was similarly confirmed with coefficients of skew (.684) and kurtosis (.134) within bounds. The assumption of linearity was also confirmed. Homoscedasticity was also absent based on the scatterplot between the unstandardized predicted values and the standardized residuals. Hence, the assumptions were met for the linear multiple regression for this model (Norusis, M.J., 2006, p. 221).

<sup>11</sup> Before the analysis to detect potential moderator variables was undertaken all continuous variables were mean centred. New variables were computed by multiplying each variable against another. The continuous mean centred variables were also dummy coded by conducting a median

split on the variable in order to collapse other variables over levels of these continuous mean centred variables. Eighteen scatterplot graphs resulted from this process and the  $R$  values for the two regression lines were compared in order to evaluate the strength of the moderator relationship. “Level of intellectual disability in sample” moderated the degree of relevance “LOG of sample size of study” had on Cohen’s  $d$  effect size such that sample size was more relevant to the Cohen’s  $d$  calculations when the sample was composed of persons with severe to profound ID versus samples composed of all levels of ID. The new moderator variable was computed by multiplying “LOG of sample size of study” by the “level of intellectual disability in sample” and subsequently used in the final linear multiple regression.

<sup>12</sup> The inclusive definition for self-care involved “normalized activities related to maintaining a person’s hygiene and health and often characterized as activities of daily living” (e.g. ADL’s, hygiene, eating, toileting, grooming, showering and bathing, selecting clothing, dressing and undressing). Communication skills were defined as “skills aimed at more functional and effective communication with others” (e.g. language or language development, receptive, expressive, or non-verbal communication). Academic skills included those “activities directed toward the development of skills taught within normalized classroom settings or schools” (e.g. number and time concept, reading, writing, and quantitative skills). The definition for social skills was limited to “activities that foster or are a direct expression of social engagement with others in ways that are considered socially appropriate” (e.g. socialization, social skills, social interaction, peer social interaction, staff social interaction, and social behaviour). Physical development was a uniform domain with effects only computed in cases where studies reported “physical development” measures. The definition of the community living/ functional independence domain was both inclusive and exclusive in nature. The definition presupposed

“activities or events that are directly a function of the community environment or representative of the individual expressing his or her autonomy” (e.g. independent function, responsibility, self-direction, independent living, community integration, autonomy, clothing care, preparing meals, serving meals, cleaning house, table manners, residential or community activities and domestic management). This definition excluded those activities included within the self-care domain. The occupational skills domain was defined by “activities or skills aimed at vocational expertise or gaining employment” (e.g. occupational domestic/general, prevocational or vocational skills). Finally, the definition for cognition included those “abilities or skills reflective of cognitive development” (e.g. multi-cognitive skills, general cognition or oriented and remembering).

Table 1

Average effect size across level of intellectual disability and domains of adaptive behaviour

Adaptive Behaviour Domain	Study Variables						<i>t</i>	Sig.
	"All Levels of ID"			"Severe and Profound ID"				
	<i>M<sub>d</sub></i>	<i>SD</i>	<i>n<sup>a</sup></i>	<i>M<sub>d</sub></i>	<i>SD</i>	<i>n<sup>a</sup></i>		
Global score	.35	.32	21	.14	.14	3	1.15	.263
Self-care	.69	.23	5	.26	.67	8	1.36	.200
Communication skills	.25	.13	5	.03	.14	6	2.70	.025
Academic skills	.35	.20	5	.15	.00	1	.89	.424
Social skills	.46	.22	12	1.33	.00	1	-3.74	.003
Physical development	.07	.07	3	.20	.03	2	-2.40	.096
Community living/ functional independence	.50	.32	35	.42	.43	19	.81	.424
Occupational skills	.41	.21	6	n/a	n/a	n/a	n/a	n/a
Cognition	.76	.16	4	.09	.31	3	3.81	.012

<sup>a</sup>*n* represents the number of effect sizes computed across studies



Table 2

Average effect size across research design and domains of adaptive behaviour

Adaptive Behaviour Domain	Study Variables						<i>t</i>	Sig.
	"Own-control"			"Matched-comparison"				
	<i>M<sub>d</sub></i>	<i>SD</i>	<i>n<sup>a</sup></i>	<i>M<sub>d</sub></i>	<i>SD</i>	<i>n<sup>a</sup></i>		
Global score	.20	.23	14	.51	.33	10	-2.75	.012
Self-care	-.10	.10	6	.88	.37	7	-6.28	.000
Communication skills	.10	.20	7	.21	.08	4	-1.07	.313
Academic skills	.22	.09	2	.36	.23	4	-.838	.449
Social skills	.26	.13	5	.69	.29	8	-3.11	.010
Physical development	.18	.04	3	.04	.05	2	3.66	.035
Community living/ functional independence	.34	.31	30	.64	.36	24	-3.28	.002
Occupational skills	.18	.04	2	.52	.14	4	-3.21	.033
Cognition	.09	.31	3	.76	.16	4	-3.81	.012

<sup>a</sup>*n* represents the number of effect sizes computed across studies

Table 3

Average effect size across community living environment and domains of adaptive behaviour

Adaptive Behaviour Domain	Study Variables						<i>t</i>	Sig.
	Group-home			Community general/undifferentiated				
	<i>M<sub>d</sub></i>	<i>SD</i>	<i>n<sup>a</sup></i>	<i>M<sub>d</sub></i>	<i>SD</i>	<i>n<sup>a</sup></i>		
Global score	.44	.33	14	.26	.13	7	1.35	.192
Self-care	.88	.37	7	-.10	.09	6	6.28	.000
Communication skills	.25	.13	5	.03	.14	6	2.70	.025
Academic skills	.35	.20	5	.15	.00	1	.889	.424
Social skills	.53	.32	13	n/a	n/a	n/a	n/a	n/a
Physical development	.07	.07	3	.20	.03	2	-2.40	.096
Community living/ functional independence	.53	.36	32	.38	.35	22	1.58	.123
Occupational skills	.41	.21	6	n/a	n/a	n/a	n/a	n/a
Cognition	.76	.16	4	.09	.31	3	3.81	.012

<sup>a</sup>*n* represents the number of effect sizes computed across studies

Table 4

Average effect size across adaptive behaviour instrument

Instrument	<i>n</i> <sup>a</sup>	<i>M<sub>d</sub></i>	<i>SD</i>
Adaptive Behavior Scale	50	.31	.22
Behavioral Development Survey	6	.53	.20
Developmental Disability Quality Assurance Questionnaire	3	.29	.21
Minnesota Developmental Programming Scales	10	.54	.18
Quebec Scale of Adaptive Behaviour	4	.27	.26
New Jersey Client Assessment Form	6	.73	.14
Vineland Adaptive Behavior Scales	1	.91	n/a
Scales of Independent Behavior	1	.59	n/a
Activity Pattern and Skill Indicator	32	.17	.34
Inventory of Individual Characteristics	5	.42	.21
Progress Assessment Chart	1	1.18	n/a
Inventory for Client and Agency Planning	6	.11	.18
Vineland Social Maturity Scale	1	.43	n/a
Developmental Record	4	1.34	.01
Street Survival Skills Questionnaire	9	.92	.15

<sup>a</sup>*n* represents the number of effect sizes computed across studies

Table 5

Correlations and linear multiple regression of predictor variables on Cohen's *d* effect size

Variables	Cohen's <i>d</i>	Publication year of article (pub_yr)	Logarithm of sample size (sam_sizLG)	Square root of male percentage of sample (per_malSQRT)	Type of community environment (comm_env)	Square root of follow-up interval (fu_interSQRT)	Research design (res_des)	sam_sizLGx dis_lev	<i>B</i>	Std. Error	□	Sig.
pub_yr	-.13								-.007	.003	-.201	.021
sam_sizLG	.11	.24							.540	.141	.365	.000
per_malSQRT	.03	.53	-.09						.017	.072	.020	.814
comm_env	-.37 <sup>a</sup>	-.32	-.42	-.15					-.203	.067	-.272	.003
fu_interSQRT	.29 <sup>a</sup>	.13	.25	.09	-.37				.030	.020	.117	.133
res_des	.51 <sup>a</sup>	.27	.04	.41	-.53	.46			.371	.065	.521	.000
sam_sizLGx	-.01	.48	.67	.23	-.58	.39	.34		-1.53	.312	-.538	.000
dis_lev												
								Intercept =	13.08			
Means	.397	1991.99	1.66	7.45	.35	3.66	.48		-.07			
<i>SD</i>	.360	10.14	.24	.42	.48	1.41	.50		.13			
											<i>R</i> <sup>2</sup> =	.469
											Adj. <i>R</i> <sup>2</sup> =	.440
											<i>R</i> =	.685 <sup>b</sup>

<sup>a</sup>*p* < .01

<sup>b</sup>*p* < .001

Table 6

Weighted linear multiple regression of predictor variables on Cohen's *d* effect size

Variables	<i>B</i>	Std. Error	$\beta$	z-score
Publication year of article	-.006	.006	-.176	-1.07
LOG of sample size	.506	.241	.366	2.10 <sup>a</sup>
SQRT sample % male	-.004	.126	-.005	.032
Community environment	-.189	.124	-.257	-1.52
SQRT follow-up interval	.029	.033	.125	.870
Study research design	.356	.111	.530	3.20 <sup>b</sup>
Moderator: LOG of sample size by disability level	-1.40	.598	-.472	-2.34 <sup>a</sup>

Intercept = 10.915

 $R^2 = .457$ Adj.  $R^2 = .427$  $R = .676^c$ <sup>a</sup> $p < .05$ <sup>b</sup> $p < .01$ <sup>c</sup> $p < .001$

Table 7

Answers provided for the random sample of questions

Question	Response 1	Response 2	Response 3	Response 4
ATS #2: Has the person accepted the transition now? Yes No Please list two indicator of this:	Yes: Not dropping to the floor in protest, following routines.	Yes: Being with the association for 20 years.	Yes: Her behaviour has been manageable and she likes participating in home activities.	Yes: She works well with staff and gets along with the program routine. She hasn't had any behaviour problems since the first few weeks of residence.
ATS #11: How appropriate do you feel this setting is for the individual? Describe why you feel this way:	Needs improvement: He lives in a small area and he could use more space to move.	Needs improvement: Difficulties with housemates (supported living environment recommended).	Excellent: She is happy here and fits in well with staff and the other residents.	Excellent: She is a good fit with the other residents, has staff with experience with her, and her behaviours have stopped for the most part.
ATS #38: Does the individual participate in daily household activities? If so, how?	Yes: Watch meal prep.	No	Yes: She participates in activities with staff and residents, helps with cleaning (her room and the living room).	No

<p>ATS #59: What choices can the person make?</p>	<p>Choosing snacks.</p>		<p>If there is an option for whether she goes out to an event or staying in.</p>	<p>Very few because she's non-verbal and has visual problems.</p>
<p>ATS #62: Has the person experienced any hospitalizations? Yes/No If so, for what reason?</p>	<p>No.</p>	<p>No.</p>	<p>Yes: Flu – dehydration.</p>	<p>No.</p>
<p>ATS #67h: Are there other areas that have changed? Other?</p>	<p>Stronger, faster, with a more explosive temper and attempts to injure staff with greater ferocity. A more stable gait.</p>			
<p>ATS #68: What main factors are responsible for the person's well-being in their new setting?</p>	<p>Routine,</p>	<p>Routine, protocols and consistency among staff.</p>	<p>Staff are able to help her when she needs it and she gets to do the activities she enjoys.</p>	<p>We have staff who care for her and are able to support her needs.</p>
<p>DSIF #8: What self-care activities do staff members provide for the individual?</p>	<p>Meal prep, bathing, dressing, eating assistance.</p>	<p>Routine, schedule/ reminders.</p>	<p>Picking out clothes, dressing a bit, food prep., wash hair sometimes, laundry.</p>	<p>Bathing/hygiene, dressing, laundry, meals, toileting, etc.</p>

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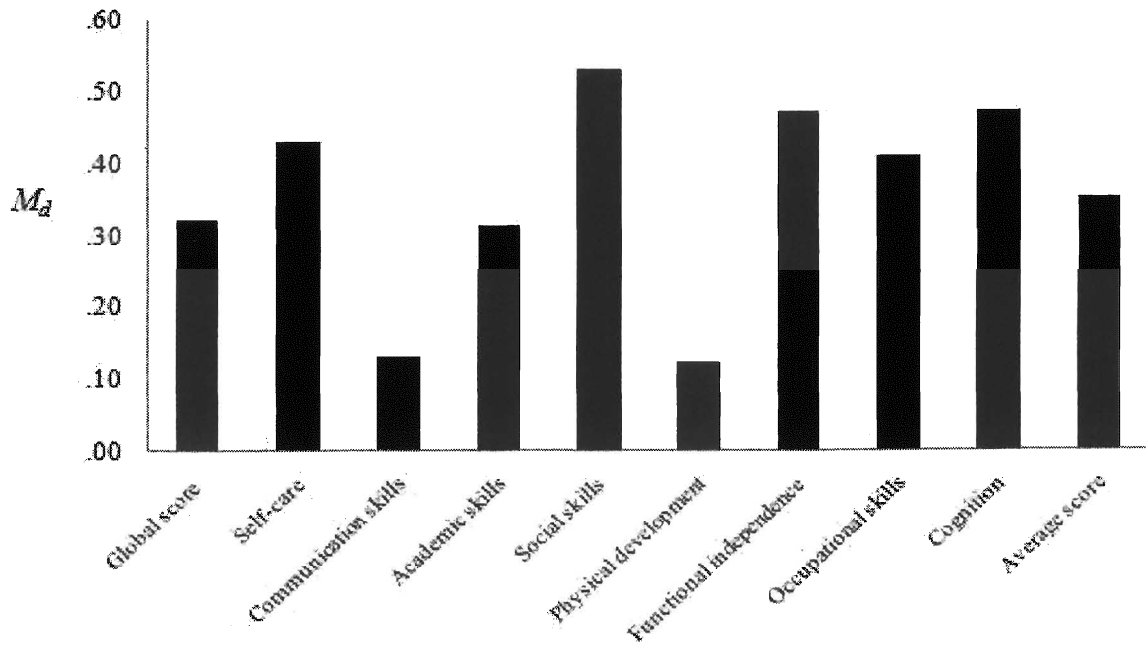
Figure Caption

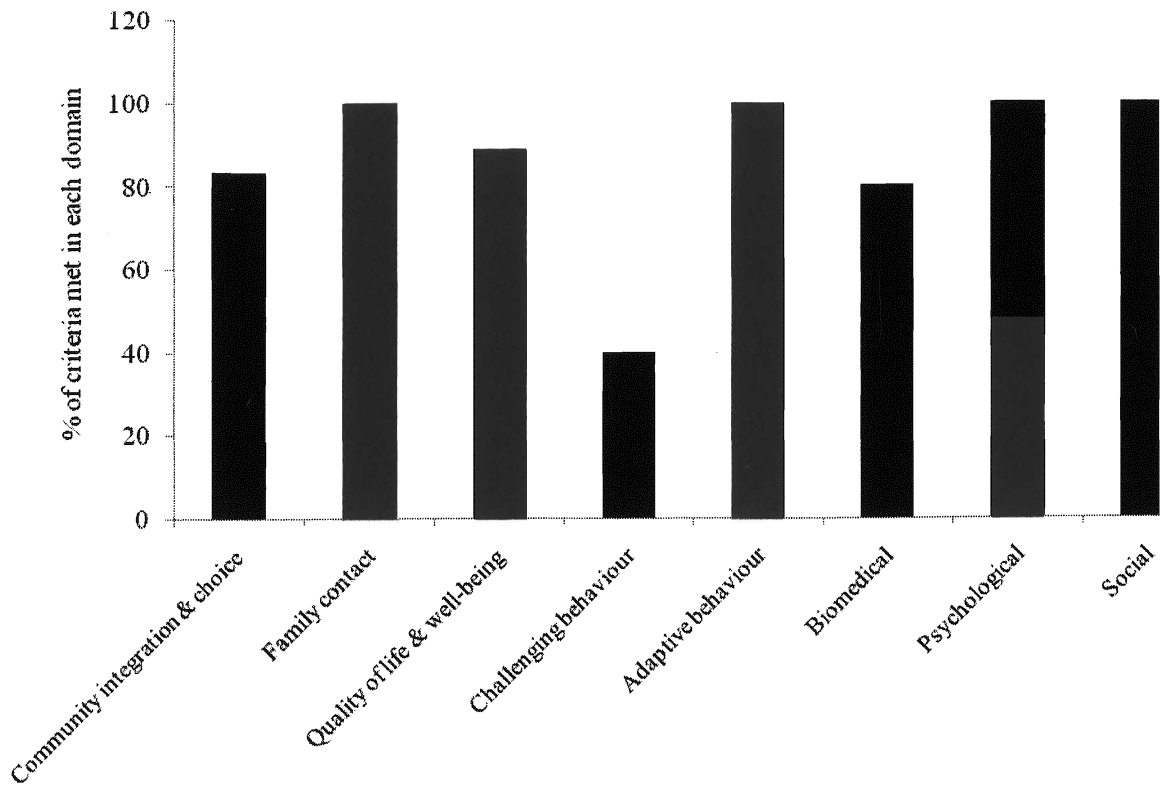
*Figure 1.* Average effect size across domains of adaptive behaviour

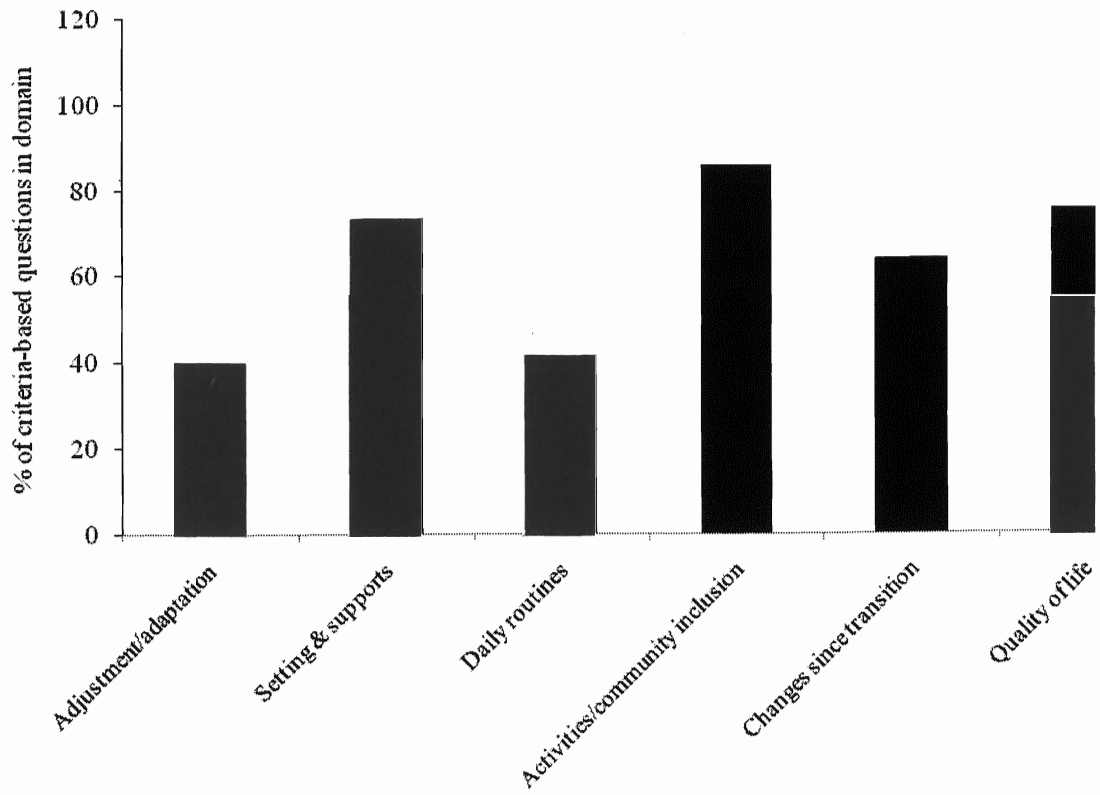
*Figure 2.* Percentage of criteria met by the ATS and DSIF in each domain

*Figure 3.* Percentage of questions in ATS domains related to the criteria









Appendix A

Original Agency Transition Survey

**AGENCY FOLLOW-UP SURVEY FOR INDIVIDUALS TRANSITIONED TO THE COMMUNITY FROM A MENTAL HEALTH CENTRE**

PLEASE have the following survey completed by 2 individuals working together to gain consensus. The two individuals should be those who know the person best since the transition to your agency. If the two people cannot reach agreement then please note this.

We have attached a copy of the Transitional Plan for you to compare the current situation with that which was recommended.

Thank you for your help.

**A. Adjustment/adaptation to the transition**

1. How well did the individual adapt to the new situation? *Extremely well/ Required little transitional adjustment/ Moderate Transitional Adjustment/ Significant challenge in Adjusting to the Transition*

2. Has the person accepted the transition now? Yes No Please list two indicators of this:

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3. If so how long did it take for the transition to be accepted? \_\_\_\_\_

4. Has the person developed strong relationships with staff? *Yes/ No* Please list two indicators of this:

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5. Has the person developed strong relationships with peers? *Yes/ No* Please list two indicators of this:

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**B. Setting and Supports**

6. Type of home: group home ( ), apartment ( ), family home ( ) other ( ) \_\_\_\_\_

7. Is this the type of home that was recommended in the Transition Plan? *Yes/ No*

8. If not why was a change recommended? \_\_\_\_\_

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9. How many people with disabilities live with the person in his or her home? \_\_\_\_\_

10. Does the person have a room of his or her own? *Yes/ No*

11. How appropriate do you feel this setting is for the individual?  
*Excellent/Good/Adequate/ Needs Improvement/ Poor*

Describe why you feel this way: \_\_\_\_\_

12. What is the current ratio of staff to this individual during the day ( : ); at night( : ), in the community ( : )?

13. Is the staffing sufficient to meet the person's needs? *Yes/ No*

14. Is the staffing consistent with recommendations in the attached Transition Plan? *Yes/ No*

15. Did the staff receive training prior to the transition of this person to your setting? *Yes/ No*

16. Do you feel this was sufficient and appropriate training? *Yes/ No*

a. If not what was needed that was not provided? \_\_\_\_\_

17. Complete the following about the professional services the person receives.

<b>Professional Services</b>	<b>Currently receives (Yes/No)</b>	<b>Frequency of Access</b>	<b>Were these recommended in the Transition Plan?</b>	<b>Why were professional services added or deleted from the Plan?</b>
Physician				
Dentist				
Behavior Therapist				

Psychiatrist				
Physiotherapist				
Occupational Therapist				
Speech/ Communication				
Social Worker				
Neurologist				
Psychologist				
Other				

18. Were there services recommended that were unavailable but still needed? *Yes/ No*

19. Are the support services sufficient for the individual? *Yes/ No*

a. If no, what else is needed? \_\_\_\_\_  
 \_\_\_\_\_

20. Are the support services of appropriate quality for the individual? *Yes/No*

a. If no, why not? \_\_\_\_\_  
\_\_\_\_\_

**C. Daily Routines**

21. What time of day does the person awake on weekdays \_\_\_ weekends \_\_\_?

22. Is the person awoken or does he/she awake themselves? Self Other

23. What time is breakfast on weekdays \_\_\_\_\_ weekends \_\_\_\_\_?

24. What time is lunch on weekdays \_\_\_\_\_ weekends \_\_\_\_\_?

25. What time is dinner on weekdays \_\_\_\_\_ weekends \_\_\_\_\_?

26. Does the person help in meal preparation? \_\_\_\_\_ How? \_\_\_\_\_  
\_\_\_\_\_

27. Does the individual readily eat a healthy diet? \_\_\_ If not what challenges does mealtime present? \_\_\_\_\_  
\_\_\_\_\_

28. What time is bedtime on weekdays \_\_\_\_\_ weekends \_\_\_\_\_?

29. Who initiates bedtime? Self Other

30. When does the person bathe? Daily, every other day, weekly

31. Is bath at a scheduled time or initiated by the individual? *Scheduled ( ) Self initiated ( )*

32. Is the person awakened during the night? *Yes/No*

a. If so why? \_\_\_\_\_  
\_\_\_\_\_

**D. Activities and Community Inclusion**

33. Does the person have meaningful/personally fulfilling things to do each day? *Yes/No*

34. Were these activities identified in the Transition Plan? *Yes/ No*

35. Are these new interests? *Yes/No*

36. Are there activities recommended in the Transition Plan that are not available or accessible to the person? *Yes/ No*

a. If so why? \_\_\_\_\_  
 \_\_\_\_\_

37. Does the individual exercise daily? *Yes/ No*

a. If so how? \_\_\_\_\_  
 \_\_\_\_\_

38. Does the individual participate in daily household activities? *Yes/ No*

a. If so how? \_\_\_\_\_  
 \_\_\_\_\_

39. Does the person have a day programme? *Yes/ No*

40. Does it involve leaving the home? *Yes/ No*

41. Is it individualized or participation in a group activity? *Individualized/ Group Activity*

42. How appropriate is the day programming for this individual?

*Excellent/ Very Good/ Adequate/ Needs Improvement/ Poor*

43. Has the person shown increase in independence since moving to your agency? *Yes/ No*

a. If so how? \_\_\_\_\_  
 \_\_\_\_\_

44. Rate how often the person engages in the following:

	Frequently (at least once a month)	Sometimes or rarely (less than once a month)	Never
Dining in a restaurant			
Receiving visits from friends			



Receiving visits from relatives			
Visiting friends (outside the home)			
Visiting relatives			
Telephone calls to or from family			
Telephone calls to or from friends			
Socialization with peers			
Going to place of worship			
Going to a movie			
Going shopping			
Going on a holiday			
Attending a concert or play			
Attending a sporting event as a spectator			
Visiting a social club			
Visiting a park or going for a walk			
Going to a barber/hairdresser			

Other			
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45. Were the above activities recommended in the Transition Plan? *Yes/ No*

46. Have activities that were recommended in the Transition Plan been accessed? *Yes/ No*

a. If not why? \_\_\_\_\_  
 \_\_\_\_\_

47. Are there other activities the person has experienced and enjoys? *Yes/ No*

a. Describe: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

48. Is the individual actively included in the community? *Yes/ No*

a. Please give examples: \_\_\_\_\_  
 \_\_\_\_\_

49. Has the individual had contacts with neighbourhood or general community?

*Frequently/ occasionally/ never*

50. Have these contacts been positive or negative? *Positive Negative*

Describe the nature of the contact: \_\_\_\_\_  
 \_\_\_\_\_

51. How would you describe the range of leisure and community activities to which this person has regular access?

*Excellent/ Very Good/ Adequate/ Needs Improvement/ Poor*

52. Has family and friend contact has changed since the move?

*Increased/ Stayed the Same/ Decreased*

53. Do family or friends help the individual relative to advocacy, support/advice, or emotional support? *Yes/ No*

Please explain: \_\_\_\_\_  
\_\_\_\_\_

54. Has the individual's new setting affected the relationships with family and friends? *Yes/ No*

What is the effect? \_\_\_\_\_  
\_\_\_\_\_

55. Has the individual gone with family or friends on an overnight stay since the transition?  
*Yes/ No*

a. Is this more or less than before moving to your agency? \_\_\_\_\_

56. Has the individual shared meals with family or friends since the transition? *Yes/No*

a. Is this more or less than before moving to your agency? \_\_\_\_\_

**E. Changes since Transition**

57. Does the person make choices in his/her own day? *Yes/ No*

58. Has choice-making increased? *Yes/ No*

59. What choices can the person make? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

60. How relevant is the Transition Plan to the person today?

*Not relevant/ Somewhat relevant/ Very relevant*

61. Has the person experienced a change in medical status/ health? *Yes/ No*

a. If so how? \_\_\_\_\_  
\_\_\_\_\_

62. Has the person experienced any hospitalizations? *Yes/ No*

a. If so for what reason? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

63. Has the person experienced behavioural challenges? *Yes/ No*

64. If so are behavioural challenges greater or less than expected from the Transition Plan?

*Greater/ About the same/ Less*

65. Were the recommendations for managing behaviour problems in the Transition Plan followed? *Yes/ No*

a. If not why? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

b. If so, were they effective? *Yes/ No*

66. Has the individual required police contact? *Yes/ No*

If yes please describe event: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

67. Are there other areas that have changed? Please describe:

Diagnoses?

Interests?

Mental Health?

General adaptive skills?

Self-care skills?

Social skills?

Communication?

Other?

**F. Quality of Life**

68. How would you rate the quality of life of this person today?

*Excellent/ Good/ Adequate/ Needs Improvement/ Poor*

a. Why did you rate it this way? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

69. What main factors are responsible for the person's wellbeing in their new setting? \_\_\_\_\_

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70. What factors could you recommend to improve the status of the person's wellbeing their new setting? \_\_\_\_\_

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a. Why have they not been accessed? \_\_\_\_\_

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71. Are their *new plans* for the person beyond the Transition Plan that was provided? *Yes/ No*

a. What the plans for this person in the future? \_\_\_\_\_

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Please comment on any area you wish in this section: \_\_\_\_\_

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Thank you for your time in completing this very important follow-up survey.

Agency: \_\_\_\_\_

Date: \_\_\_\_\_

Appendix B

Demographic and Supplemental Information Form

**Demographic and Supplemental Information Form**

Please answer the following questions to the best of your knowledge:

**Personal Information**

1. Please identify the individual's current diagnosis and level of intellectual disability.  
\_\_\_\_\_
2. What is the individual's current age at the time of this assessment? \_\_\_\_\_

**Setting**

3. How long has the person resided in his/her current environment? \_\_\_\_\_
4. Is this the same setting they moved into after leaving the Bayview Dual Diagnosis Program? YES/NO
  - a. If not, where did he/she reside in the intervening time?  
\_\_\_\_\_
5. How would you characterize the type of setting the person is currently living in? (Please circle one of the following) *Group-home/ Small-supported living environment/ Semi-independent living/ Extended semi-independent living/ Long-term care facility/ Other*

**Adjustment**

6. How has the person adapted since moving to the community? (Please circle one of the following) *Continued improvement in functioning and skills/ Initial gains that have stabilized/ No change in functioning and skills from previous environment/ Declines in functioning and abilities*

**Self-Care**

7. Approximately what proportion of the person's self-care activities does the person complete themselves? (Please provide an estimated percentage) \_\_\_\_\_
8. What self-care activities do staff members provide for the individual? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Communication**

9. How does this person commonly communicate with others? (Please circle one of the following) *Verbally/ Semi-verbal/ Sign/ Visual communication system (i.e. PECS or picture board)/ Other*

10. Does this person have a functional communication system based on his/her needs and/or abilities? If so, what form does it take?

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11. What types of supports/services could be offered to the individual to help mediate his/her communication needs?

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12. Were these needs previously identified in the Transition Plan? YES/NO

13. What barriers or challenges exist preventing the person from receiving these supports?

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**Other Supports/Services**

14. Are there any services or supports that you believe the person would benefit from or require that they are not currently receiving? YES/NO

a. If so, what are they? \_\_\_\_\_

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15. What barriers or challenges (if any) exist preventing the person from receiving these supports?

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Appendix C

Critical Analysis Tally Sheet

<b>Critical Analysis Tally Sheet</b>	
<b>Criteria</b>	<b>Item relating to criterion</b>
<b>Community integration and choice:</b>	
Use of community services	<input type="checkbox"/>
Level of community integration	<input type="checkbox"/>
Types of choices available	<input type="checkbox"/>
Degree of choice expression	<input type="checkbox"/>
Recreational activities	<input type="checkbox"/>
Occupational activities	<input type="checkbox"/>
<b>Family contact:</b>	
Frequency of contact in home	<input type="checkbox"/>
Frequency of contact outside of home	<input type="checkbox"/>
Level of involvement or advocacy	<input type="checkbox"/>
Activities associated with family contact	<input type="checkbox"/>
<b>Quality of life and well-being:</b>	
Global quality of life	<input type="checkbox"/>
Physical well-being/health	<input type="checkbox"/>
Material well-being	<input type="checkbox"/>
Social well-being	<input type="checkbox"/>
Productive well-being	<input type="checkbox"/>
Civic well-being	<input type="checkbox"/>
Level of community participation	<input type="checkbox"/>
Quality of social networks	<input type="checkbox"/>
Level of support	<input type="checkbox"/>
Environmental quality	<input type="checkbox"/>
<b>Challenging behaviour:</b>	
Form of challenging behaviour	<input type="checkbox"/>
Frequency of behaviour	<input type="checkbox"/>
Duration of behaviour	<input type="checkbox"/>
Intensity of behaviour	<input type="checkbox"/>
When change(s) occurred	<input type="checkbox"/>
<b>Adaptive behaviour:</b>	
Form of adaptive behaviour	<input type="checkbox"/>
Frequency of behaviour	<input type="checkbox"/>



Supports/training provided		
Skill level		
When change(s) occurred		
<b>Biomedical:</b>		
Medical		
Psychiatric		
Medications/medication reactions		
Syndromes		
Neurological state		
<b>Psychological:</b>		
Psychological features		
Psychological skills deficits		
<b>Social:</b>		
Environmental features		
Interpersonal events/features		
Programmatic features		
Physical features		
<b>Total:</b>		

Appendix D

Client or Substitute Decision Maker Consent Form for Release of Information

**Consent Form (Substitute Decision Maker)**

**Date:** Jan. 5, 2009

**Project Title:** The Practical Application of a Meta-Analysis Examining Deinstitutionalization Adaptive Behaviour Outcomes in Piloting a Transitional Questionnaire for Adults with Intellectual Disabilities.

**Principal Student Investigator: Jeffery Hamelin**

**Faculty Supervisor: Dr. Dorothy Griffiths**

**MA Student, Centre for Applied Disability Studies**

**Associate Dean, Faculty of Social Sciences**

**Centre for Applied Disability Studies**

**Centre for Applied Disability Studies**

**Brock University**

**Brock University**

**Tel: 905-228-4598**

**(905) 688-5550 Ext. 4069**

**[jh07ng@brocku.ca](mailto:jh07ng@brocku.ca)**

**[dgriffiths@brocku.ca](mailto:dgriffiths@brocku.ca)**

**INVITATION**

We are requesting that staff from the agency complete an evaluation of the progress of individuals who have been transferred from Bayview Dual Diagnosis Program back to the community within the past 18 months. The purpose of this study is to examine the efficacy of a transitional questionnaire in assessing the outcomes for service users; your family member has been identified as an individual who had received services from the Bayview Dual Diagnosis Program in the past 18 months.

This survey was developed by Brock University Faculty in the Centre for Applied Disability Studies and further informed by investigating areas of adaptive behaviour that commonly influence the outcomes of community transition. The survey will examine issues of changes since the transition in quality of life, adjustment, supports, daily routines, activities and community inclusion.

**WHAT'S INVOLVED**

As participants, the primary staff members for the individual have been asked to complete an Agency Survey and Demographic and Supplemental Information Form commenting on the outcome of the community transition. No personally identifying information is being collected, rather staff are commenting on their observations of the success of the transition (in the areas of adjustment, setting and supports, daily routines, activities and community inclusion, changes since the transition and quality of life).

### **POTENTIAL BENEFITS AND RISKS**

This research should benefit both the Bayview Dual Diagnosis Program and the agency by identifying successful ways to promote adaptation during transitions and noting any potential supports that are not presently being received but may be needed. We believe that it will also assist the agency in reflecting on their current practice and may assist in providing feedback as to enhancing quality of life for the individual. Consenting to, or refraining from consenting to, the release of information will in no way effect agency services for the client in question. **There are no known or anticipated risks associated with participation in this study.**

### **CONFIDENTIALITY**

All information collected with the survey will be kept confidential and strictly anonymous. Neither the individuals name nor any other identifying information will be used when the staff members complete the survey. Data collected during this study will be stored in a locked filing cabinet in the Research Lab of Dr. Dorothy Griffiths. Data will be kept for 12 months after which time all data pertaining to the study will be destroyed using a confetti paper shredder. Access to this data will be restricted to the Principal Student Investigator, his Faculty Supervisor, and research assistants (Senior or Master's level students from Brock University). In consenting to the release of this information you will not have access to the surveys and responses made by staff members.

### **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to allow the staff members to complete the transitional survey. Further, you may inform the staff members that you wish them to withdraw from this study at any time, up to the point that they submit complete surveys, and you or they may do so without any penalty or loss of benefits to which you or they are entitled. Identified staff members will only be asked to provide the information if you consent to the release of this information.

### **PUBLICATION OF RESULTS**

Feedback about the outcomes will be provided to the Bayview Dual Diagnosis Program and to the staff members of participating agencies approximately 2-3 months after data collection is complete. Should you wish a copy of the study please request this from Nancy Pilon at the Bayview Dual Diagnosis Program (telephone 705-549-3181); Results of this study may be published in professional journals and presented at conferences.

### **CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact the Faculty Supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (file # 08-211). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

**CONSENT FORM**

I agree to allow the staff members to participate in the study described above for my family member and to forward the survey without identifying information to the researchers. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Appendix E

Client Plain Language Consent Form for Release of Information

**Consent Form Plain Language Statement for Clients**

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To the client of interest,

Two of your staff members have been asked to fill out forms about when you moved to your group home. We want to know how they feel the move went and how they think you are doing at your home. We want to know more about your home, what you do there and the kinds of things your staff members do for you. We also want to know more about what you do in the community and what your behaviour is like since you moved. We really want to know if your staff members think that you like your home and if there is anything else that they can do for you to help you enjoy your life there.

When your staff members fill out the forms they will not use your name so no one but your staff members will know that the information is about you. All the forms will be kept locked up so no one but us can see the information. You will not be allowed to read or see what staff members have said. The information from a whole group of people will be used to see how well individuals are doing in their group homes. You can help us to learn how to help people to have better lives in their group homes.

The information will not be used for anything other than what we have talked about already. We will tear up the forms after a year so that they won't be used for anything else.

It is up to you whether you want your staff members filling out these forms or not. You will not get into any trouble if you help us or if you decide not to help us. Either way, your staff will keep helping you in your home. You can tell your staff if you want them to fill in the form or not. It is your right to choose. If you want your staff members to stop filling out the forms after they have started you can do that too. If this is what you want just tell one of you staff members that you don't want the forms filled out; they will stop and the forms will be tore up. Staff members will only fill out the forms if you want them to and let them by signing your name on this form.

If you will let your staff members fill out the forms please sign your name below on the line where it says "name." Thank you very much for your help with this.

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Consent Form – continued

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I will let my staff members fill out the forms about when I moved to my home. Someone read to me or I have read about the forms on this page. If I had questions my staff members answered them or found out the answers for me. I understand that I can tell my staff members to stop filling out the forms at any time.

Name: \_\_\_\_\_

Date: \_\_\_\_\_

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Witness Verification:

Witness will ask the individual the following questions and continue to explain the consent until the person understands and is able to agree or choose not to agree to participate:

Why do they want to know about how well you are doing?

Will they make sure that no one except the people doing the study knows what on the form?

Can you say no if you do not want your staff to fill in the form?

Can you tell your staff members to stop filling in the forms?

Witness that the person understands the consent process as described and has agreed.

Witness Name: \_\_\_\_\_

Witness Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Appendix F

Letter of Invitation and Instructions for Managers

**LETTER OF INVITATION & INSTRUCTIONS FOR MANAGER: RESEARCH  
DISSEMINATION** Jan. 5, 2009

**Title of Study:** The Practical Application of a Meta-Analysis Examining Deinstitutionalization Adaptive Behaviour Outcomes in Piloting a Transitional Questionnaire for Adults with Intellectual Disabilities

**Principal Student Investigator:** Jeffery Hamelin, Master of Arts Student, Centre for Applied Disability Studies, Brock University **Faculty Supervisor:** Dr. Dorothy Griffiths, Associate Dean Faculty of Social Sciences, Brock University

I, Jeffery Hamelin, MA student, from the Centre for Applied Disability Studies, Brock University, invite your agency to participate in a research project entitled The Practical Application of a Meta-Analysis Examining Deinstitutionalization Adaptive Behaviour Outcomes in Piloting a Transitional Questionnaire for Adults with Intellectual Disabilities.

The purpose of this research project is to examine the efficacy of a transitional survey in assessing the outcomes for service users who have been transitioned to community settings within the past 18 months. This survey was developed by Brock University Faculty in the Centre for Applied Disability Studies and further informed by investigating areas of adaptive behaviour that commonly influence the outcomes of community transition.

Your agency's investment and participation in the study will take approximately 3 weeks from the time of receipt of the surveys and their completion. If your agency should wish to participate please take the following steps:

1. Contact the client(s) in question (or his/her/their substitute decision maker(s)) and proceed with the process for the consent to the release of this information by staff members (using the consent forms provided). If the client(s) in question consent to the release of their information proceed to the next step (otherwise return the materials in the envelopes provided). Please note that consenting clients or substitute decision makers also have the right to withdraw from the study or revoke their consent to the release of information at any time.
2. Identify staff members who were closely involved in the transition and presently support the pre-identified clients who were transitioned to your agency (i.e. those regularly involved in the scheduling, oversight, or implementation of the transition and can appropriately comment on a number of issues related to it as well as the client's present activity level and community involvement).

3. Distribute the enclosed letters of invitation and consent forms to identified staff members with envelopes and collect them once completed or refused (give potential participants 2 days after the receipt of the forms to complete and return them).
4. Forward completed consent forms to the Faculty Supervisor.
5. Distribute copies of the Agency Survey and Demographic and Supplemental Information Form to identified participants with envelopes (acknowledge a deadline of 2 weeks for the surveys to be completed and returned). Note: the same staff member can be asked to complete a survey on more than 1 transition they were involved in. Let staff members know whether you agree to let them use work time to complete the surveys.
6. Forward completed surveys and forms to the Faculty Supervisor.

This research should benefit your agency with an assessment of the effectiveness of some of your client transitions as well as the important elements involved. You will be provided with feedback on the assessment of the surveys after this analysis has been completed. Furthermore, your use of the survey can continue after the initial piloting is complete if you find the instrument and feedback useful in your practice.

No companies or agencies are sponsoring this research. This is a multi-site research project involving a number of agencies serving adults with intellectual disabilities.

If you have any pertinent questions about your agencies rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)  
If you have any questions, please feel free to contact me. Thank you

**Jeffery Hamelin**  
MA Student, Centre for Applied Disability Studies

**Brock University**

**St. Catharines ON L2S 3A1**

**Tel: 905-228-4598**  
**jh07ng@brocku.ca**

**Dr. Dorothy Griffiths**  
Associate Dean Faculty of Social Sciences

**Brock University**

**St. Catharines ON L2S 3A1**

**Tel: 905-688-5550 Ext. 4069**  
**dgriffiths@brocku.ca**

**This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file #08-211)**



Appendix G

Letter of Invitation for Participants

**LETTER OF INVITATION (Staff Members)**

Jan. 5, 2009

**Title of Study:** The Practical Application of a Meta-Analysis Examining Deinstitutionalization Adaptive Behaviour Outcomes in Piloting a Transitional Questionnaire for Adults with Intellectual Disabilities

**Principal Student Investigator:** Jeffery Hamelin, Master of Arts Student, Centre for Applied Disability Studies, Brock University

**Faculty Supervisor:** Dr. Dorothy Griffiths, Associate Dean Faculty of Social Sciences, Brock University

I, Jeffery Hamelin, MA student, from the Centre for Applied Disability Studies, Brock University, invite you to participate in a research project entitled The Practical Application of a Meta-Analysis Examining Deinstitutionalization Adaptive Behaviour Outcomes in Piloting a Transitional Questionnaire for Adults with Intellectual Disabilities.

The purpose of this research project is to examine the efficacy of a transitional survey in assessing the outcomes for service users who have been transitioned to community settings within the past 18 months. This survey was developed by Brock University Faculty in the Centre for Applied Disability Studies and further informed by investigating areas of adaptive behaviour that commonly influence the outcomes of community transition.

Your investment and participation in the study will take approximately 1-4 hours (coordinated with another staff member) in completing an agency survey and demographic and supplemental information form on the transitional experience of one (or more) of the clientele whose transition you were closely involved with. You may also be asked to comment on present activity levels and the types of services this client receives. Whether these surveys can be completed during work hours is at the discretion of your individual managers. <sup>1</sup>

This research should benefit you and your agency with an assessment of the effectiveness of some of your client transitions as well as the important elements involved. It may inform your practice in aiding with future transitions for your clientele. You will be provided with feedback on the assessment of the surveys after this analysis has been completed. Furthermore, your use of the survey can continue after the initial piloting is complete if you and your agency find the instrument and feedback useful for your practice.

No companies or agencies are sponsoring this research. This is a multi-site research project involving a number of agencies serving adults with intellectual disabilities.

If you have any pertinent questions about your agencies rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca). If you have any questions, please feel free to contact me. Thank you

**Jeffery Hamelin**  
MA Student, Centre for Applied Disability Studies

**Brock University**

**St. Catharines ON L2S 3A1**

**Tel: 905-228-4598**  
**jh07ng@brocku.ca**

**Dr. Dorothy Griffiths**  
Associate Dean Faculty of Social Sciences

**Brock University**

**St. Catharines ON L2S 3A1**

**Tel: 905-688-5550 Ext. 4069**  
**dgriffiths@brocku.ca**

**This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file # 08-211)**

Appendix H

Consent Form – Participating Staff

**Consent Form (Staff Members)**

Date: Jan. 5, 2009

Project Title: The Practical Application of a Meta-Analysis Examining Deinstitutionalization Adaptive Behaviour Outcomes in Piloting a Transitional Questionnaire for Adults with Intellectual Disabilities.

**Principal Student Investigator: Jeffery Hamelin**

**Faculty Supervisor: Dr. Dorothy Griffiths**

**MA Student, Centre for Applied Disability Studies**

**Associate Dean, Faculty of Social Sciences**

**Centre for Applied Disability Studies**

**Centre for Applied Disability Studies**

**Brock University**

**Brock University**

**Tel: 905-228-4598**

**(905) 688-5550 Ext. 4069**

**jh07ng@brocku.ca**

**dgriffiths@brocku.ca**

**INVITATION**

You are invited to participate in a study that involves research. You and your agency have been invited to complete an evaluation of the progress of individuals who have been transferred from Bayview Dual Diagnosis Program (BDDP) back to the community within the past 18 months. The purpose of this study is to examine the efficacy of a transitional survey in assessing the outcomes for service users.

This survey was developed by Brock University Faculty in the Centre for Applied Disability Studies and further informed by investigating areas of adaptive behaviour that commonly influence the outcomes of community transition. The survey will examine issues of changes since the transition in quality of life, adjustment, supports, daily routines, activities and community inclusion.

**WHAT'S INVOLVED**

As a participant, you will be asked to complete an Agency Survey commenting on 1 community transition for a client with which you were closely involved. These clients or their substitute decision makers have already consented to the release of this information. It is possible that you may be asked to fill out more than one survey if you were involved with more than one client transition from BDDP within the past 18 months. Participants will be paired (i.e. yourself and another staff member who was involved in the same transition). You will be asked to complete the survey and Demographic and Supplemental Information Form and as much as possible come

to a consensus with your answers. If there are questions that you cannot come to a consensus on please complete the question and note that a consensus was not reached on that item. Participation will take approximately 1-4 hours of your time (depending on how long it takes you to complete the survey with the other participating staff member). **If you choose to participate, please return the signed consent form to your Program Coordinator (in the provided envelope) who will then forward it on to the Principal Student Investigator (PSI).**

### **POTENTIAL BENEFITS AND RISKS**

This research should benefit you and your agency with an assessment of the effectiveness of some of your client transitions as well as the important elements involved. It may inform your practice in aiding with future transitions for your clientele. You will be provided with feedback on the assessment of the surveys after this analysis has been completed. Furthermore, your use of the survey can continue after the initial piloting is complete if you and your agency find the instrument and feedback useful for your practice. Study participation, or lack thereof will in no way effect your employment. **There are no known or anticipated risks associated with participation in this study.**

### **CONFIDENTIALITY**

All information you provide is considered confidential; your name will not be included or, in any other way, associated with the data collected in the study. Furthermore, because our interest is in the average responses of the entire group of participants, you will not be identified individually in any way in written reports of this research. Data collected during this study will be stored in a locked filing cabinet in the Research Lab of Dr. Dorothy Griffiths. Data will be kept for 12 months after which time all data pertaining to the study will be destroyed using a confetti paper shredder. Access to this data will be restricted to the Principal Student Investigator, his Faculty Supervisor, and research assistants (Senior or Master's level students from Brock University). The clients about whom you are being asked to comment on, their substitute decision makers and your managers will not have access to your specific responses.

### **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time, up to the point that you submit complete surveys, and may do so without any penalty or loss of benefits to which you are entitled. The client(s) in question is also free to withdraw or revoke their consent to the release of information at any time. If you wish to withdraw simply place the study forms in the provided envelopes with a note identifying that you wish to withdraw from the study. Upon receipt, the researchers will destroy the provided forms using a confetti paper shredder.

### **PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available approximately 2-3 months after data collection is

complete. As all study information will be directed to the PSI through your manager/program coordinator general feedback will be forwarded to her for dispersal to you.

**CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact the Principal Student Investigator or the Faculty Supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (file # 08-211). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

**CONSENT FORM**

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_